



Queen Margaret University
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MANAGING NOT MENDING: NAVIGATING END OF LIFE DYSPHAGIA CARE IN ADULTS WITH HEAD AND NECK CANCER – SPEECH & LANGUAGE THERAPISTS' EXPERIENCES

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Key to Abbreviations

AHP	Allied Health Professional (UK). This generic term encompasses a wide group of professionals including Speech and Language Therapists, Physiotherapists, Occupational Therapists, Dietitians, Art Therapists, Music Therapists and others.
CSM	Clinical Services Manager
eol	end of life
HNC	Head and Neck Cancer
MDT	Multi-disciplinary Team
MCN	Managed Clinical Network
NES	NHS Education for Scotland
NHS	National Health Service, UK
QOL	Quality of life
RCSLT	Royal College of Speech & Language Therapists (UK)
SLT	Speech and Language Therapist (UK). This professional title is also referred to as Speech-Language Pathologist in the USA and Australia.

Definition of terminology and acronyms

Aspiration

Aspiration is defined as ‘the action or process of drawing breath’ (Oxford dictionaries, 2016). In terms of dysphagia management, aspiration is generally regarded as the inhalation of food and fluids into the airway to a level below the vocal cords. This can result in development of ‘aspiration pneumonia’ which can be fatal.

Bolus

A bolus is:

‘a small rounded mass of a substance, especially of chewed food at the moment of swallowing.’ (Oxford Dictionaries, 2016).

HNC

Head and Neck Cancer:

‘.. a group of cancers (larynx, oral cavity, oropharynx, hypopharynx, nasopharynx, major salivary gland, nose and sinuses and cancer of the bones of the jaw) that have many common features but also important differences in biological behavior.’ National Head and Neck Cancer Audit (2014) pp7.

NBM

Refers to the medical term ‘nil by mouth’ where someone is advised not to have any oral intake.

RCSLT

Royal College of Speech and Language Therapists (UK). This is the professional body of SLTs in the UK.

Abstract

To date there has been minimal published investigation into the experiences of Speech and Language Therapists in providing end of life dysphagia (swallowing) care to adults with head and neck cancer. In addition, the question of how Speech & Language Therapists are prepared to carry out this role and what they consider to be necessary in order to do this effectively has not been fully considered.

This study aimed to make a contribution towards addressing this issue by adopting a qualitative approach, interviewing practising SLTs and providing an opportunity for them to discuss their experiences of working in this field. The research area aligned with a phenomenological methodology which was felt to be the most suitable approach to facilitate a detailed and rich description of their experiences. The intention was that the findings may inform future practice and professional education.

Eleven participants consisting of two pilot participants, a focus group of three participants and six individual, main participants from across four health boards in Scotland took part in semi-structured interviews. Interview topics were identified from a broad initial literature search. An Interpretative Phenomenological Analysis approach was taken. The study revealed a wealth of rich data and four super-ordinate themes: 'A risk worth taking' 'Under your skin', 'Communication isn't always wonderful' and 'Trained and equipped'.

The findings suggest that there is a considerable emotional impact on SLTs engaged in this type of work and that multi-disciplinary communication is not always effective. Finally, the findings suggest that there is currently a gap in professional training and support.

Key Words and phrases

Speech and Language Therapy

Head and Neck Cancer

Dysphagia

Swallowing

End of life

Training and preparation

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Layout of the thesis

This thesis is divided into six broad chapters. Each chapter includes a number of clearly labelled sub-sections. It is intended that this layout will enable the reader to readily select specific areas of interest and navigate through the thesis with ease. The intention is to provide a clear, logical progression and accessible format.

Chapter Summaries

Chapter one considers the background and introduction to the topic

Chapter two provides a broad literature review

Chapter three discusses the selection of methodology

Chapter four sets out the detailed findings of the selected themes

Chapter five discusses the findings in relation to the literature

Chapter six considers the conclusions of the study

References

Appendices

1 Introduction

This research seeks to explore what experience Speech and Language Therapists (SLTs) have of providing end of life dysphagia care to people with head and neck cancer. The study concerns SLTs within four Health Boards forming part of the National Health Service in Scotland. It explores how prepared SLTs feel for providing this care from the point of view of the SLT participants. The findings are discussed in terms of their implications for practice. Recommendations are made regarding undergraduate, post-graduate, workplace and professional needs.

Background

Development of the Question: broad statement of the perceived problem

The topic of end of life (eol) is something that everyone will come to address at some point whether personally or in relation to family, friends or others. Some discomfort is reported in considering this issue (Llewellyn et al, 2016, Nia et al, 2016). The result of this lack of dialogue about end of life can be that when faced with a situation where a person is confronted with the issue, whether on a personal or professional level, they may feel somewhat unprepared (Nia et al, 2016). Within the health service in the UK, working clinicians of all specialities will encounter end of life, often from the early stage of their careers. In considering the impact of patient death on nursing staff, Wilson & Kirshbaum (2011) concluded that the available literature demonstrated an impact of patient death on healthcare workers and that there were practice development implications related to this finding. An international literature review of death anxiety amongst healthcare professionals by Nia et al (2016) reported that death anxiety was frequently reported across thirty eight selected studies since 2000. Data was collected mainly in the form of self reports by healthcare staff. Nia et al (2016) suggested a need for increased interventions to support staff in dealing with this issue. Similarly, Llewellyn et al (2016) examined death conversations in primary healthcare in New Zealand and concluded that discomfort regarding engagement in conversations about death continued to prevail. The authors suggested there was a need for additional resources to facilitate such conversations across different settings.

Carrasco et al (2015) conducted a descriptive evaluation of palliative care educational provision within undergraduate medical training across Europe and found that only 30% of countries included the subject in all universities. Carrasco et al (2015) went on to comment that a unified structure to this education was developing but that overall there remained wide variation in how this was provided. The situation is improving with some attempts to provide and evaluate the impact of multi-disciplinary palliative care training such as Ray et al's (2014) paper which describes an Australian study into multi-disciplinary palliative care education. The researchers conducted a needs assessment to identify educational topics and later went on to evaluate a video conference based multi-disciplinary palliative care education programme delivered to one hundred and one participants. The aim was to improve confidence levels in palliative care interventions across rural healthcare staff in Australia. Ray et al (2014) reported that AHPs had lower confidence in palliative care topics at the outset than nurses, medical staff and students. They also reported that in considering all participating professions, those who had 'on the job' training alone had significantly less confidence in this area of work than those who had post-graduate qualifications (Ray et al, 2014. pp 4-5).

The researchers commented that Allied Health Professionals (AHPs) were a group who reported the second greatest improvement in confidence post training after those who referred to themselves as medical staff or students. Although there was little detail of specific needs by profession, they concluded that:

'..more attention should be directed to the diverse educational needs of allied health professionals..'

Ray et al (2014)

pp7.

Whilst this study has a focus in rural Australia, it provides evidence of a changing picture with regard to education in palliative care. The authors acknowledged that the multi-disciplinary format and lower representation of AHPs, with in fact only two SLTs taking part, resulted in inclusion of topics regarded as of less relevance to the AHP group. This may indicate that some further AHP specific training would be beneficial.

It would seem that there is still some way to go before we have a workforce fully prepared and equipped to deliver quality end of life care to all those who require it regardless of setting or geographical location.

Speech and Language Therapy (SLT), as a profession, has traditionally been placed within the sphere of rehabilitation services within the National Health Service in the UK as part of the wider group of Allied Health Professionals (AHPs). SLTs work primarily with communication and swallowing impairment (i.e. dysphagia). It is suggested that SLT clinicians practicing head and neck cancer care (HNC) can be faced with a situation where clients nearing the end of life no longer require what could be termed typical dysphagia rehabilitation, where the aim is to regain function. In such circumstances, it is proposed that other needs arise such as a need to maintain or maximise function or to manage changes in functional status as the disease progresses. Within current professional training, there has been little emphasis on this aspect of SLT to date. Informal discussions with local Higher Education establishments providing SLT training in Scotland revealed a lack of direct inclusion of end of life care within existing curricula. Currently, little information is available in the UK as to what type of issues SLTs encounter when providing a service at this point in the care pathway or how prepared they feel for this role.

The author's personal motivation for conducting this research is included in the appendix (pp 177). In terms of practice as a clinician and the author's role as a manager and team lead, there is a need for an understanding of how to enable staff to provide quality care within a professionally supported environment in the workplace. Staff need knowledge of clinical, professional, legal and ethical issues which may impact on their service delivery. Patients need to be able to access the right care from appropriately trained professionals at the right time and in the most appropriate manner. The SLT profession in the UK needs clarity of vision regarding what this service should look like and how to prepare SLTs to deliver it effectively. The RCSLT professional standards (RCSLT 2006) provide a broad outline of SLT involvement in palliative care but state that more research is needed within the adult setting.

It would seem that there is a need to examine what experiences SLTs have when working with adults with HNC at the end of life. Additionally, an exploration of what is required to enable SLTs to provide an effective end of life dysphagia service to the head and neck cancer population is indicated. The research aims to establish how such findings can inform and shape understanding of future practice and educational requirements. Although there is a wealth of evidence related to swallowing disorders, SLT assessment and therapy techniques, to date there has been minimal exploration of the role within end of life care.

Starting Premise

Within the qualitative approach adopted for this research, the concept of a research hypothesis is not applicable since the aim is not to test a specific hypothesis (Silverman 2011). However, the notion of an initial starting premise is a requirement in order to retain clarity during the course of the project and to provide an adequate means of evaluation on completion. A clearly stated premise at the outset makes it easier to establish the focus of the project and its relevance and potential impact.

The starting premise is an aspiration that:

- an exploration of how SLTs experience providing this care will help to reveal what practising clinicians report as key issues
and it postulates that:
- there is currently a lack of preparation for SLTs providing end of life dysphagia care for adult head and neck cancer patients

Aims and Objectives

Aims

The study aims to contribute to the SLT profession's ability to meet the needs of this population more effectively by:

- demonstrating what practicing SLTs report as key issues in delivering this care.
- providing a basis for supporting the development of future SLT education by identifying SLTs experiences of preparation for this role.
- contributing to the SLT profession's ability to meet the needs of SLTs by identifying what they think is required to provide this care effectively

Objectives

The research therefore explores:

- What SLTs experience when providing this care (HNC and end of life)
- How SLTs experience preparation for delivering this care
- What SLTs feel is required in order to provide this care effectively

Research Question

What experiences do SLTs have of preparing for and delivering end of life dysphagia care with adult HNC patients and what do they think is needed to provide it effectively?

The research question does not specify a specific setting as although most participants worked wholly within the acute adult setting, some undertook domiciliary and community based practice. It was felt that this data might be of interest, so the research question was purposefully left open to allow inclusion of such data should it arise. The specific wording of the research question was elaborated slightly from the initial

proposal in order to make explicit the two aspects of preparation and delivery which were not clearly stated in the initial proposal however this was only related to wording and no other changes were made to the proposal or project plans.

Timeliness and significance of the study - End of life in the media

Media coverage of end of life issues has been prominent in recent years including discussions regarding the management of eating and drinking at the end of life across a range of conditions (BBC news 3rd November 2012). This is relevant to an exploration of the SLT role in terms of their potential contribution to decision-making around eating and drinking impairment at this stage of care.

BBC news coverage has recently included articles on palliative care and the needs of the dying patient (BBC news 15 May and 20 May 2015). Simon Chapman of the National Council for Palliative Care on 20 May 2015 stated that:

'There is a tension between the need to cure and the need to care'.

This clearly resonates with the topic of this research.

Why is it worth asking the question?

An exploration of what specific experiences SLTs report in providing this care and what preparation they feel they have had to do this would be a useful addition to the current evidence base. A detailed exploration of these experiences would help to inform the profession, service commissioners and educators about the areas of greatest need. Ultimately, the findings should be able to make a valuable contribution to SLT professional development and may be applicable to other similar healthcare professions.

What this research does not do

This research does not explore the broader professional experiences of SLTs outside of managing HNC and end of life care. The research does not include SLTs outside Scotland and only concerns SLTs working within the NHS in Scotland. This research does not consider paediatric dysphagia and only considers the adult population (18yrs +).

Relevance and Impact

This research may have relevance to and an impact upon the following areas:

- Ageing population.

End of life care may become more of an issue for AHPs as the proportion of older people with potentially complex, age-related co-morbidities increases in synchrony with anticipated demographic changes (ONS, 2015).

- Other AHP groups.

Improving education and facilitating further integration of AHPs within end of life settings. This research may demonstrate issues of wider relevance to other similar professional groups.

- Other researchers, Managed Clinical Network colleagues, and the RCSLT.

Sharing the findings with multi-disciplinary and research audiences may contribute to professional development across SLTs and other professional groups.

Context - NHS Setting

The National Health Service (NHS) is the UK public body responsible for providing healthcare to the population. Founded in 1948, its stated purpose is to deliver healthcare to all, free at the point of delivery. In the Parliamentary address outlining the proposed development of a national health service, this was presented broadly as a

universal health service providing the best health advice and treatment to all regardless of financial status (Hansard, 1946).

The NHS delivers healthcare across a range of settings from the acute hospital environment to the community setting. This study is set predominantly within the acute sector of the NHS in Scotland.

Demographics - Ageing population

The most recent data from the Office for National Statistics in the UK describes current increases within the groups aged 66 and 67 and 45 to 55 years of age with projections for 2039 suggesting a marked increase in the population at older ages (ONS, 2015). This has implications for the future workforce in that SLTs will be required to appropriately manage an increasingly aged caseload.

Dysphagia

Dysphagia is defined as a '*difficulty or discomfort in swallowing as a symptom of disease*'. The term derives from 'dys' meaning 'bad or difficult' and the Greek 'phagia' meaning 'eating' (Oxford dictionaries, 2016).

Oropharyngeal dysphagia

Oropharyngeal is defined as '*the part of the pharynx that lies between the soft palate and the hyoid bone*' (Oxford Dictionaries, 2016). Therefore oropharyngeal dysphagia relates to a difficulty in swallowing arising from this region.

The Development of a role in managing oropharyngeal swallowing disorders - Speech and Language Therapy as a Profession

The profession of Speech and Language Therapy has its roots firmly in the rehabilitation of communication impairment. Historically a typical caseload would have included referrals for children or adults with developmental or acquired language or

articulation disorders such as difficulties with understanding or producing speech following a stroke, structural anomalies affecting speech production etc.

Jerri Logemann, an American Speech-Language Pathologist (the US term for SLTs) was one of the early researchers instrumental in the development of the field of oropharyngeal dysphagia, having begun exploring swallowing problems in the 1970s (Logemann, 1979). She was not alone in this area of research and in fact recognition of the SLT role in swallowing disorders had been evident for some years, as indicated in the early publication by Court and Harris (1965) which included a recommendation to consider swallowing assessment in paediatric therapy. However, Logemann's work could be considered pivotal in the development of the role of the SLT in oropharyngeal swallowing. Logemann has therefore been considered in some depth.

Logemann described her view of the origins of the role for Speech Language Pathologists in the management of oropharyngeal dysphagia. One aspect of the role was described as having derived from chewing and swallowing exercises where the primary aim was to improve speech articulation in the paediatric cerebral palsy population (Logemann, 1984).

Logemann provided a detailed description of each phase of the swallowing process which included the initial oral-preparatory stage followed by the oral, pharyngeal and oesophageal stages. This was followed by an account of swallowing disorders which might occur at each stage along with diagnostic procedures and treatment approaches. (Logemann, 1984).

Essentially, the oral preparatory phase consisted of the acceptance of a bolus of food or liquid into the mouth in order to be swallowed, whilst the oral stage included manipulation and formation of a bolus along its transit towards the pharynx in readiness for swallowing. The pharyngeal phase consisted of the trigger of the swallow reflex and the mechanism of movements enabling the bolus to enter the pharynx including the protection of the airway which is a crucial aspect of safe swallowing. The final oesophageal phase consisted of the bolus passing through the upper oesophageal sphincter and entering into the oesophagus (Logemann, 1984).

Disorders of each stage of swallowing included factors such as reduced strength or mobility, reduced sensation, reduced triggering of the swallow reflex, impaired airway protection and reduced cricopharyngeal opening (the musculature at the top of the oesophagus). Logemann discussed a range of disorders resulting in such deficits along with the potential impact on the swallow in terms of resultant aspiration into the airway before during and after the triggering of the swallow reflex. These included congenital or acquired neurological deficits as well as surgical and radiotherapy cases (Logemann, 1984).

Langmore et al (1998) explored risk factors for aspiration across a reasonably large sample of patients with multiple diagnoses (n = 187) and long term follow up. Langmore concluded a predictive relationship between swallowing status and the potential to develop aspiration pneumonia which can prove fatal. This suggested the importance of appropriate and timely management of oropharyngeal dysphagia.

Diagnostic tools at the time, (which indeed remains essentially the case in current times), included the 'bedside evaluation' and the 'modified barium swallow'. The former of which consisted of an oral motor evaluation of cranial nerve function and motor/sensory function as well as oral trials. This was considered to be highly accurate in evaluating the oral-preparatory and oral phases of the swallow. The latter diagnostic tool used a fluorographic image of the moving swallow and was regarded as the most accurate way to assess all phases of the swallow (Logemann, 1984).

Treatment approaches suggested by Logemann included compensatory strategies such as postural changes, texture modification, modification of bolus size, temperature, placement and swallowing therapy approaches such as strengthening exercises. (Logemann, 1984).

Susan Langmore's paper (Langmore, 1999) attempted to outline the issues faced by SLTs in clinical practice within adult dysphagia, reflecting similar issues to Logemann and highlighted the need for multi-disciplinary working at this early stage in the development of the role. This view was later supported by Leslie et al (2003) who also

highlighted the need for timely access to an SLT and attempted to describe common causes and implications of dysphagia.

In subsequent decades, the SLT role in oropharyngeal dysphagia management has developed such that there is now a wealth of published material of varying degrees of evidential quality. This material documents aspects of oropharyngeal swallowing impairment as well as the evaluation of a variety of assessment and treatment methods including both clinical and instrumental approaches.

There have also been a number of attempts to survey and classify what constitutes typical assessment intervention across the UK, Ireland, Australia, Canada and the US revealing some consistency and some variation in practice. Bateman et al (2007), Carnaby et al, 2013, Gonzales-Fernandez et al, 2013, Martino et al (2004), Mathers-Schmidt et al (2003), Vogels et al (2015). The matter of what should be part of the assessment repertoire is still very much an ongoing and evolving debate, but these studies also provide a window on SLT practice in terms of identifying important components of the assessment process.

Vogels (2015) included a summary of key assessment features which seems to be representative of the majority of studies. The dysphagia related items are listed below:

Dental status

Respiratory status

Posture and positioning

Management of oral secretions

Presence of tubes in situ

Patient's ability to participate

Oral trials (i.e. trying different textures, quantities etc of oral intake)

Oro-motor examination

Oral hygiene

Patient/family/carer interview

Hydration status

Nutritional status

Social history

Medical history

The field of oropharyngeal dysphagia for SLTs has continued to develop and now forms a large part of the typical acute caseload, to the extent that in some cases there are now concerns being expressed about this caseload dominating practice to the exclusion of other areas such as communication therapy (Foster et al, 2014). There is also some suggestion in these quarters, of a need to reconsider how acute caseloads are prioritised within the acute setting (Foster et al 2014). If there is a desire to build on a patient centred focus of care, this would seem an appropriate suggestion.

Head and neck cancer - overview

The National Head and Neck Cancer Audit for England and Wales suggests this definition of head and neck cancer:

‘.. a group of cancers (larynx, oral cavity, oropharynx, hypopharynx, nasopharynx, major salivary gland, nose and sinuses and cancer of the bones of the jaw) that have many common features but also important differences in biological behaviour.’

National Head and Neck Cancer Audit (2014) pp7.

Incidence, staging, sites and intervention

Although it is difficult to establish an accurate picture of incidence due to the variable nature of how head and neck cancers are recorded (variation in which sites are included within the head and neck category), Warnakulasuriya (2009) suggested that head and neck cancer is thought to be the sixth most common cancer globally.

Argiris et al (2008) offered a succinct overview of head and neck cancer including its pathogenesis, risk factors and staging. In summary most HNCs are squamous cell carcinomas often associated with lifestyle risk factors such as smoking and alcohol intake.

Staging of tumours is via the TNM system which assigns a staging according to tumour extent (T), nodal involvement and extent (N) and presence of metastatic disease (M). Broadly this involves staging from 1 to 4 for each of the three areas according to severity (Roland et al (2016)).

Treatment approaches include surgery (often requiring reconstruction with tissue flap repairs from donor sites on the patient's own body), radiotherapy (including intensity modulated radiotherapy) and chemotherapy. Diagnosis includes direct clinical examination as well as methods of imaging such as CT (computerised tomography), MRI (magnetic resonance imaging) and PET (photo-emission tomography) scans. A number of complications can arise such as late stage reactions to radiotherapy, the involvement of surrounding healthy tissue and local or distant recurrence (Argiris et al, 2008).

There is also increasing recognition of a rise in head and neck cancer in younger age groups which is thought to be linked to the prevalence of the human papilloma virus (HPV) (Vigneswaran and Williams, 2014).

Recent developments in the management of HNC have focussed on developing an understanding of the detailed molecular, metabolic and genetic expressions or over expressions of specific cancers in this region. The intention being to use this information to develop a range of targeted treatments to inhibit progression. Preventative measures such as vaccination are being developed as in the case of Epstein Barr Virus which can be associated with the development of nasopharyngeal cancers (Pezzuto et al, 2015). One of the potential implications of these new targeted treatments however, is the resultant ethical debate concerning prolongation of life and the perceived quality of that life in terms of symptom burden.

The latest revision of TNM (tumour, node, metastases) classifications for head and neck cancer also reflects these changes as for the first time there will be a classification for oropharyngeal tumours arising as a result of P16 immunohistochemistry over-expression (Brierley et al, 2016).

Development of the SLT role in HNC

Logemann (1979) conducted an early study into the impact of head and neck surgical procedures on oropharyngeal swallowing in relation to oral transit times and motility. Although the study only concerned thirty cases, it employed objective fluorographic assessment measures to assess oral transit times for a range of different consistencies of bolus. Logemann reported an observed severe impact on oral transit times and bolus motility for patients who had undergone floor of mouth or tonsillar resections. This was further explained in terms of the type of impairment, with those undergoing floor of mouth surgery demonstrating a slower oral phase and those with tonsillar/pharyngeal surgery showing impairment in the oral and pharyngeal phases of the swallow. Patients who had undergone laryngectomy did not demonstrate this impairment although the swallow was also slower for these cases post-operatively (Logemann et al, 1979). This study provided one of the first detailed examinations of the impact of head and neck cancer on swallowing and remains of key relevance today. Since this early study, the SLT profession has developed a key role in the management of head and neck cancer in terms of both speech and swallowing and SLTs are now widely accepted as a core member of the multi-disciplinary team (NICE 2004).

Palliative Care and end of life care - overview

Palliative care is defined by the World Health Organisation as:

'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.

(WHO, 2016) www.who.int/cancer/palliative/definition/en/.

There is increasing recognition of the need for development of palliative care services both in terms of access and awareness. The global atlas for palliative care (WHO, 2014) identifies a number of unmet needs including stating that:

‘..The vast majority of health professionals worldwide have little or no knowledge of the principles and practices of palliative care..’ (WHO, 2014) pp27

End of life and end stage care

The General Medical Council (UK) makes the distinction between end of life and end stage care which it defines in the following manner:

End of life care:

‘..patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes those patients whose death is expected within hours or days; those who have advanced, progressive incurable conditions; those with general frailty and co-existing conditions that mean they are expected to die within 12 months; those at risk of dying from a sudden acute crisis in an existing condition; and those with life-threatening acute conditions caused by sudden catastrophic events..’ (GMC, 2010).pp 86

End stage care:

‘The final period or phase in the course of a progressive disease leading to a patient’s death’. (GMC, 2010).pp 87

Two prominent names come to the fore when considering the development of palliative and end of life care in the UK, Dame Cicely Saunders and Elizabeth Kubler-Ross. Dame Cicely Saunders is noted for her role in the establishment of the hospice movement having been instrumental in the development of the first UK hospice, St Christopher’s Hospice in London. She provided an illustrative description of her motivation and actions in this regard, in the foreword to the Oxford Textbook of Palliative Medicine (1993). Overall, this concerned the recognition of a gap in service

provision for those nearing the end of life and a drive to implement best practice, core values and holistic approaches to care, which remains pertinent to this day.

Elizabeth Kubler-Ross published her book 'On Death and Dying' in 1970. This book has since become a well respected and widely sourced publication. In the book, Kubler-Ross sought to discuss all aspects of death and dying and proposed a five stage

process towards acceptance of death. This concerned an initial stage of denial and isolation followed by anger, bargaining, depression and final acceptance (Kubler-Ross, 1970). Consideration of the needs of the family as well as the dying patient made this book, at the time, quite unique since the norm was to consider the medical aspects of patient care as the priority. The book remains a worthy contribution to the development of palliative and end of life care and is still a valuable addition to any healthcare professional's learning in preparation for entering this sensitive field.

Development of the SLT role in palliative care and end of life

As a result of increasing specialisation, many SLTs working in specific fields encounter patients with a deteriorating condition (e.g. progressive neurological diagnoses, dementia, cancer etc). These clinicians are required to deal with situations which may be considered to be outside of the typical rehabilitation scenario. Professional guidance and advice regarding appropriate management of deterioration has been limited. In addition, SLTs have not typically been fully included in consultations or guideline development in some of these areas. The concept of continued oral intake with risk has long been acknowledged by SLTs. Hansjee (2013) discussed the development of a multi-disciplinary protocol to assist with risk feeding in London. This pathway was reported to have resulted in more prompt decision making around oral feeding by the team and thereby improved patient care. The picture is changing with increasing discussion of the topic, particularly with regard to stroke care. Sommerville et al, (2016) reported on a programme of 'feeding with acknowledged risk', again with a multi-disciplinary focus. Within end of life care however, there still appears to be some way to go before SLTs are routinely included in the multi-disciplinary team.

Preparation – personal stance and theoretical framework

The next section describes the background to the study in terms of the personal stance taken and the selection of a theoretical framework for the research.

Personal Stance - quantitative versus qualitative

In preparing to conduct research it is necessary first to identify a clear standpoint from which to begin as the researcher's own world view and assumptions influence all future actions related to the research in question. For example, a researcher taking the view that the world consists of constants which can be isolated, examined and measured in a systematic and replicable manner would align most closely with a positivist, quantitative or 'scientific method' approach (Pernecky, 2016). In this way the researcher would be likely to identify a question to be answered and would approach the task in a specific manner, informed by their own take on the world. This might include designing a study where, a hypothesis is formed and an experimental process defined, in which to test the hypothesis. In simple terms, the stance taken would be that anyone given the right controlled conditions should be able to replicate the same results due to the rigor of the experimental process. This would ensure that no stone is left unturned in accounting for possible confounding factors towards identifying a universal truth, with the researcher taking on a remote orchestrating role rather than directly influencing the process.

However, another researcher attempting to examine a similar issue, may take the stance that each individual sees and experiences the world differently as part of a social context. This researcher as a result, would expect to find differences across individuals and would also consider the impact of their own beliefs and interactions on the process and on the resultant product of those interactions. This type of viewpoint would align more closely with a qualitative or interpretative approach (Hennink et al, 2011).

This author is of the view that there is certainly a place for the scientific method which laudably attempts to mitigate potential variation and improve replicability towards identifying constants, however, human variation needs to be accounted for even within

this arena. If we strive to establish absolute knowledge of what is undeniably true i.e. a quantitative perspective, then we also need to understand the impact of the individual in order to properly account for their role in how research is approached, conducted and interpreted. An attempt to understand this process, informs both our knowledge about human beings as well as our awareness of how researcher based flaws in quantitative research methods occur. It is argued therefore that there is value in considering the human aspect of research more carefully.

Ontological position

This research takes the stance that what is considered to be reality is specific to the individual concerned. Each of us perceives the world in our own way and as a result we will all have a slightly different take on our experiences and therefore different realities. This is clearly demonstrated when people describe their experiences of the same event often with very different interpretations (Barbour, 2008).

An individual's sense of what is true for them can be affected by their own preconceptions, emotions and previous experiences as well as the influence of social interactions. An example from SLT clinical practice might be the use of 'personal construct therapy' in the SLT management of dysfluency, the clinical term for stammering. Here the clinical emphasis is on exploring the individual's own internal beliefs or constructs about the reality of the dysfluency and attempting to reframe them in a more balanced manner. A leading early proponent of this approach in SLT was Peggy Dalton, who applied the personal construct psychological view of Kelly (1955) into the field of Speech and Language Therapy (Dalton, 1983). The aim here was to employ personal construct therapeutic approaches to enable the person with dysfluency to explore and change their internal constructs about fluency, in order to view the world in a different light. Ultimately, the aim was to enable the person to cope more effectively as a result of adopting a changed perspective – essentially an attempt to change their reality of the impairment.

Epistemological position

It is the author's opinion that the social aspect of knowledge development cannot be ignored; the act of observation of others, striving for conformity and the use of communication to share and elaborate on experiences must significantly impact on what knowledge is formed within all individuals concerned. In this way, each person's own sense of 'knowledge' is likely to differ to varying degrees on the basis of social connectedness and how each individual interprets events (Pernecky, 2016)

As previously stated, this research takes the view that some aspects of the world are relative constants and therefore there will be elements of shared knowledge which are inherently similar, but the impact of the individual on how knowledge is formed at a personal level, cannot be assured with certainty. In an attempt to define epistemology, Schwandt (2007) discussed the quandary of seeking a shared certain knowledge within the context of a qualitative viewpoint which asserts that each individual's experiences will be different.

In summary, the researcher identified an affiliation with a subjective, relativist rather than an objective, realist research paradigm and ontological position, and an interpretivist rather than a positivist stance. Within this framework, data gathering would be initiated from an inductive, qualitative viewpoint, rather than a deductive quantitative approach. In terms of designing the study, this would align with the use of interviews and inductive methods rather than experimental or deductive methods (O'Gorman and MacIntosh, 2015). Without doubt this view influenced what kind of research question was of interest, how it was developed, the selection of appropriate qualitative methodologies and how the literature was viewed. It is important to recognise and own this aspect of the research in order to properly account for how it was conducted.

Theoretical Framework

The researchers overall ontological and epistemological stance also influenced the selection of theoretical framework. With a flexible, social approach to how knowledge is formed and an acceptance of individual variance, any theoretical framework employed would need to be able to account for multiple influences, both within and external to the individuals and across the data. As part of a previous learning experience, the researcher had encountered systems thinking and systems theories within the context of organisational change (Burnes, 2009). One of the earliest proponents of systems theory was Ludwig von Bertalanffy who in his early publication on general systems theory, attempted to redefine the dominant world view of science based upon positivist principles. This prevailing view involved the notion that in order to understand something, it was necessary to break it down into its constituent parts and examine each part in detail independently. In this way, the mechanics of what was being investigated could be revealed and understood. General systems theory, however, sought to describe an all encompassing explanation of how seemingly different aspects of science, psychology and economics were linked and could be shown to reveal underlying similarities in terms of their functioning as a system (Bertalanffy, 1969).

Systems theories essentially move away from considering constituent parts to an examination of the whole in context. They essentially concern the view that many varied aspects of life from biology to commerce to large complex organisations, exhibit similar features in terms of how they operate as a whole system and indeed connect with one another. Systems theories consider that complex systems are made up of individual elements, each with their own specific boundaries which work together by means of patterns, relationships and interactions, to work as a whole system which has an overall system boundary. Systems can be closed or open. Closed systems consist of elements which do not interact with the wider environment, whilst open systems interact outside of themselves across their own boundary and into that of other systems. Information is inputted, processed and outputted in a non-linear manner. Most systems incorporate feedback which can be either positive, allowing adjustments to be made furthering the progress towards effective output, or negative, inhibiting or

exacerbating barriers towards effective output. Each individual element of the system has its own boundary as does the whole system combined but all aspects of the whole system interact. The result is that the product of the whole system is greater than that of its individual elements. The whole system seeks to maintain equilibrium by constantly adjusting and evolving dynamically. Change in one aspect of a system will impact on the whole system, which in turn responds and adjusts in order to maintain the systems integrity (Capra and Luisi, 2014).

Systems can become overwhelmed when input exceeds the capacity of the system. Chaos theory arose from consideration of the response of a whole system to being overwhelmed – the system then becomes chaotic in attempting to right itself and regain equilibrium. In doing so, new outcomes and solutions can arise (Capra and Luisi, 2014).

The justification for the decision to adopt a systems theory approach relates to the core nature of systems theories in terms of how the constituent parts of a system relate to one another and interact, in order to enable and maintain the functioning of the system as a whole.

This seemed to resonate with the overall stance of the project in that viewing the research question within such a framework would enable the researcher to consider and account for a variety of influences around, within and between participants and the researcher, thereby revealing multiple aspects to each experience of reality. It is of course the researchers duty to select the most appropriate framework to do justice to the findings and it was felt that employing a systems framework was the most likely to fulfil this requirement.

Ecological systems

Whilst systems theories can be applied to numerous, broad situations such as economics, communication systems or the environment, social ecological systems were of particular interest in view of the human aspects of the study. Ecological

systems theories are concerned with the social environment and the interactions that occur within it. It was considered that viewing the individual as part of a dynamic, ecological system could be readily adapted to an exploration of an individual within a complex workplace. The ecological aspect would allow the freedom to consider how development occurs within that environment rather than only considering its interaction and functioning.

Uri Bronfenbrenner's ecological systems theory was of particular interest and although this theory is concerned with child development, it was felt that it could readily be applied to the workplace in healthcare (Bronfenbrenner, 1979). Employing this theoretical framework afforded a means of attempting to account for the multiple influences on participants and the researcher within the study with clarity. The systematic approach within this theory enables the researcher to consider the influence of specific levels of interaction around the individual. Within a complex system such as the NHS it was felt that this would provide a useful structure within which to explore the findings.

Bronfenbrenner suggested that each individual is influenced by both their immediate environment and gradually larger and more remote environments which interact in both directions as a whole system. Bronfenbrenner began with the individual at the core of the system. The first influence on the individual was termed the microsystem, which related to the immediate context of direct interactions within the home, family, peers etc. The second area of influence was termed the mesosystem, which concerned the impact of the individuals experiences within the microsystem and how that impacted on the wider environment. In the case of this study an example might be that of an SLT who has experienced close personal bereavement who may then interact differently within the wider environment of end of life care than one who had not, as a result of their own personal experiences. The next level was termed the exosystem which involved the wider system with which the individual may not have direct contact but which still exerted influence. Within this study an example might be changes within the wider healthcare organisation which the individual has not played an active role in bringing about, but the effects of which will be felt at an individual level. The wider

macrosystem is concerned with the culture, ideologies and belief systems of both the individual and the context within which they exist. This might include the wider NHS and its traditional structure, policies, workplace culture and societal norms.

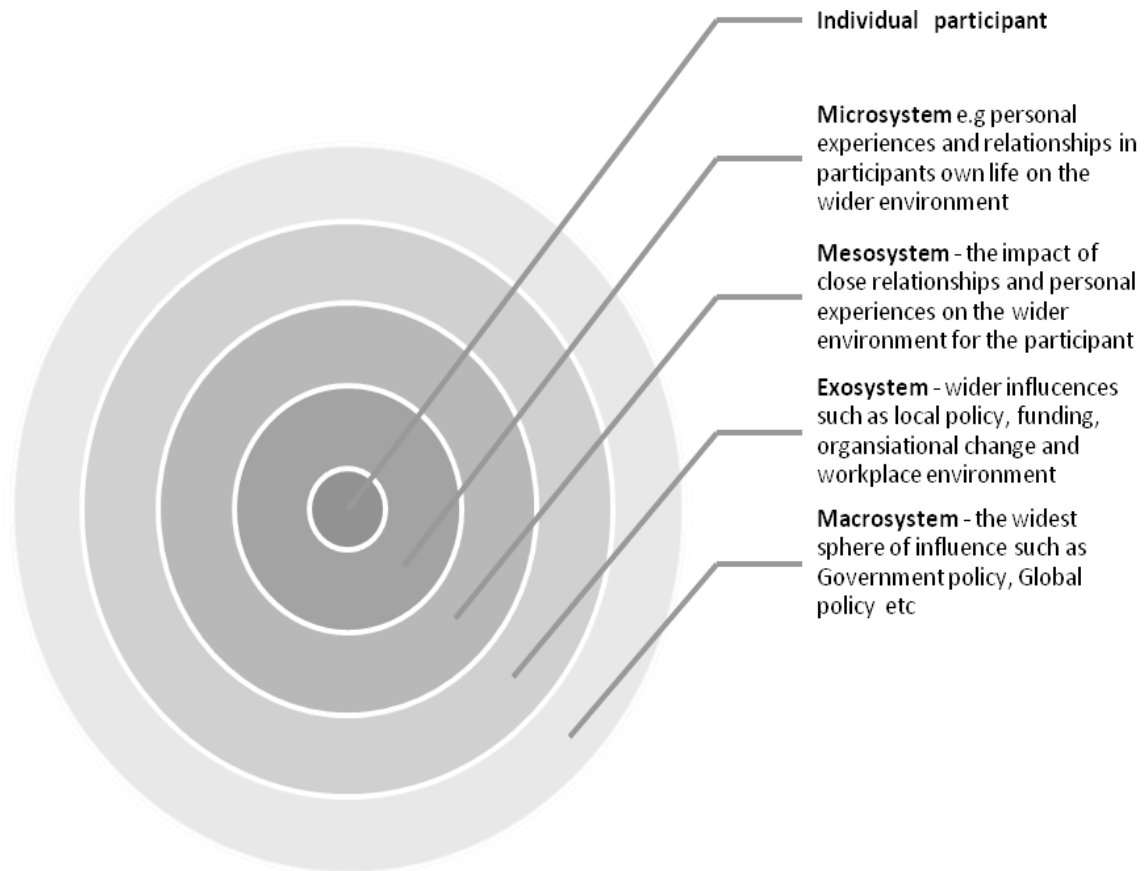


Figure 1. Bronfenbrenner's Ecological Systems Theory as applied to the data (Based on Bronfenbrenner, 1979)

The Microsystem

For all participants and the researcher, this element of the ecological system includes all aspects closest to the individual ie the home environment and close personal relationships and experiences. In the context of this study, this might also include workplace colleagues and relationships.

The Mesosystem

The mesosystem concerns the impact of those aspects of the microsystem which affect the individual within the outside environment. An example might be a member of staff who has personal issues at home which might influence how they perceive and respond to circumstances within the workplace. To some extent the individual has control over this aspect of their environment and is able to make choices and influence what happens within it.

The Exosystem

The next sphere of the ecological system is the wider local picture. The individual may have less direct contact with this aspect of the system but will still be affected by it and is able to influence it. In the example of this study, the exosystem might include aspects such as Health Board policy, Funding issues or Professional issues.

The Macrosystem

The macrosystem is the widest field of the ecological system with which the individual perhaps feels less connection but interaction and influence may still occur. Within the context of this study this might include Government policy changes, population changes or global health issues.

Having provided a broad overview to introduce the reader to the topic and context, along with an account of the author's stance and theoretical framework, the following chapter will consider the available literature pertinent to the study in more detail

2 Literature Review

This section outlines the specific approach taken to identify, review, critique and synthesise the existing literature.

Literature Review Design and Search Strategy

An initial, broad literature search was conducted in 2012 as part of the idea development stage. The purpose was to establish the current status of literature related to Speech and Language Therapy management of oropharyngeal dysphagia in end of life head and neck cancer and to critically appraise it.

On completion of the idea development stage, a detailed literature search was conducted in 2013 as part of the preparation for the research proposal. These searches were also used to inform the topics for the interview schedule. The purpose of this was to ensure that interview prompts had a firm basis in the existing literature and were not simply based on anecdotal or personal perceptions of key issues.

Four training sessions were arranged with an NHS Specialist Librarian. This proved to be invaluable in understanding the nuances of the different databases and how to make effective searches as well as how to save, retrieve and re-run searches.

Databases were searched systematically with full records of search dates, terms, combinations and number of papers identified. Searches were conducted in the same manner with the same search terms across the databases. Searches employed the Boolean operators 'or' and 'and' as well as the use of a 'wildcard' function using an asterisk after the root term, in order to find all related variants such as 'patholog*' in order to find references to pathology, pathologist, pathologies (Aveyard, 2010, Waltho et al, 2015). An example search is included in the appendix (pp 222):

In addition, reference lists from key papers and texts were used in a snowballing approach to gather further related older background/scene setting evidence, not identified by database searching. Other sources of information were searched including the Scottish Partnership for Palliative Care newsletters (SPPC, 2016) which list

national documents, conference proceedings, current research activity and updates on issues in palliative care.

The NHS Knowledge network '(Knowledgenet, 2016) also proved a useful resource. Its 'Current Information Bulletins' are quarterly updates which list recently published research and national documents on specified subjects. The bulletins relating to palliative care and head and neck cancer were particularly useful in providing an overview of existing publications.

Other sources included the Royal College of Speech and Language Therapists 'Bulletin' (RCSLT, 2016) which was monitored for relevant articles and professional activities. The author's role on the former NHS Education for Scotland 'SLT Advisory Group' (Formerly 'Think Tank') facilitated an ongoing familiarity with current professional agendas with regard to the research topic.

All searches were saved and re-run in May 2015 and September/October 2016 during preparation of the final thesis in order to ensure that the project remained aligned with current available evidence and developments.

Quality Review/Critical Analysis

Having reviewed a number of approaches, a critical analysis framework was developed to employ when evaluating search findings (Table 1 pp 27 and Table 11 Appendix pp 224). This was based upon existing critical analysis approaches including those produced by CASP (CASP, 2016), Cochrane (Cochrane library, 2016) and the RCSLT (RCSLT, 2016).

The critical analysis framework is shown on the next page. This proved to be a helpful format to enable a consistent approach to reviewing the quality of the literature.

Papers without any reference to the key aspects of the study were initially set aside at this stage however ultimately, all results were viewed in order to avoid missing any papers with a different focus but still with some aspect of interest to the research. As many of the papers concerned a high degree of anecdotal content, much of the framework was redundant in most cases however it served as a reminder of the need to seek robust evidence.

Table 1 Critical analysis Framework

Source: date/publication/ credible/where else published	
Title: Concise/informative/clear/is Q relevant	
Author: recognised/qualified/experienced/ why did they write it/ funded by whom	
Abstract: present/clearly identifies problem/states hypothesis/outline methodology	
Intro: clear aim/problem clear/limitations clearly stated	
Lit Review: up to date/Identifies underlying theoretical framework/balanced +/-lit clearly identifies need for research/omissions	
Hypothesis: does study use experimental approach/can it be tested/is it unambiguous/definitions given	
Methodology: approach clearly stated/most appropriate/+/- of approach discussed	
Sample selection: subjects clearly Identified/appropriate/location/suitable/generalisable	
Data Collection: adequately described/ validity and reliability of any instruments stated	
Ethics: approval/consent/confidentiality/anonymity method	
Results: what does it show/does it stack up/ results correctly interpreted/relevant/clearly presented	
/internally consistent/sufficient detail re inspiring reader confidence in findings/ images useful	
Data analysis: appropriate/stats correct/other variables considered in interpreting apparently significant results/all details present/omissions	
Discussion: balanced/draws on previous research/weaknesses recognised/clinical implications discussed/bias	
Conclusions: are they supported by the results/implications identified	
Recommendations: do recs suggest further areas for research/Identify how any weaknesses could be avoided	

Data abstraction/synthesis

A vast amount of literature was identified within the individual searches as a result of such broad terms. For example, the search of the ASSIA databases on 12/10/2012 for the term 'palliat*' resulted in 4452 hits. It was clear that there was very limited available output related to SLT or to all criteria under investigation. However, a wider body of evidence existed, with a focus on different aspects of the research question such as palliative care, swallowing difficulties, education and multi-disciplinary working. This provided a broader picture of the approach adopted to similar issues across other professions, other diagnoses and other countries.

On completion of the initial critical analysis, papers which were highly relevant to the study were selected. In fact, when search terms were combined with 'and' there was a very minimal return from all databases, with clear saturation of the topic identified by the same studies being shown across the databases.

The most highly relevant papers were then reviewed against a further quality analysis and categorisation sheet. This was designed to enable a more robust assessment of the relevance and quality of evidence presented (Table 12 Appendix pp 225).

Literature Search outcome

Having reviewed the outcome of all individual and combined searches and examined the strongest papers, the remaining papers with a less direct relevance were subsequently reviewed. The quality analysis and categorisation system identified a key group of the eight strongest papers overall. Each of the selected papers demonstrated specific relevance to the topic of investigation.

An example of the individual critique process is included in the (Table 11 Appendix pp 224).

The literature is presented in table format. Table two shows the key focus and preliminary evaluation of selected SLT related papers considered most relevant to the research topic. Table three represents the outcome of a detailed analysis and

comparison of each of the eight strongest papers of relevance to the research topic. This approach allowed similarities and differences to be clearly visible across the body of evidence and provided a suitable method of synthesis. Common themes became apparent.

Table four depicts the detailed analysis of eight papers primarily but not directly related to the research topic. Table five shows the detailed analysis of papers and documents related to Professional bodies, other professions and other countries. Finally, Table six includes the detailed analysis of articles and general papers related to other diagnoses and professions.

Table 2 – Key focus of the selected SLT related papers most relevant to the research topic

Author/ date	Pollens 2004	Pollens 2012	Newman 2009	Roe 2007
key info/findings/ validity	<p>Lit review: Identifies role re communication & DG based on lit search summary based on WHO 6 components PC. Case examples.</p> <p>Concludes SLT can develop strategies to add comfort and ease to QOL/support decision making + participation/support carers to care for patient/ optimal comfort and safety/ positive communication and feeding interaction/ consultative role re MDT</p> <p>Makes valid contribution re what researchers have reported SLT can bring.</p>	<p>Paper discusses how SLTs can contribute to MDT in PC to become integrated.</p> <p>IDs conflict- identifies role in PC contrasts with traditional impairment based rehab role.</p> <p>Valuable addition to 1st paper re where to go next.</p> <p>Defines role</p> <p>Case examples</p> <p>Urges SLTs to engage/research</p> <p>suggests 3 actions: Communicate with MDT/offer quality care to patient +carers/ learn about PC and educate others about SLT</p>	<p>Discusses SLT techniques in eol</p> <p>Suggests few SLTs in MDT. Increasing recognition.</p> <p>Uses cases to describe role in rehab for eol/ PC</p> <p>Good intro to topic -supports Pollens findings and inclusion of SLT in PC MDT</p> <p>Includes overview of swallow process and table of SLT strategies re DG e.g. posture/ texture /mouthcare etc</p>	<p>Conference presentation Overview of SLT in PC - concept of rehab/ evidence base to support role/ethical issues/service development. Origins of PC/ National docs/concept of rehab in PC/ need for research to highlight need and provide evidence for SLT.</p> <p>Raises need for SLT education in PC.</p> <p>Provides a coherent overview of challenges and support for SLT inclusion in PC</p>

** denotes papers with strongest content related to the research question. Bold type denotes highly relevant content.

Table 2 continued

Author /date	Roe Leslie Drinnan 2007	Eckman Roe 2005	Roe & Leslie 2010	Levy et al 2004
key info/findings/ validity	<p>Paper on non HNC DG PC experiences.</p> <p>Uses validated QOL questionnaire to examine pt experiences of non HNC pts with dysphagia in palliative care</p> <p>Prospective pilot 4 months</p> <p>11 participants</p> <p>Small sample. Authors conclude that other cancer pts in pall care experience dysphagia.</p> <p>Useful overview of dysphagia and QOL issues</p> <p>Questionnaire to explore experience – may not be ideal. Authors recommend qualitative research</p>	<p>Paper discusses SLT inclusion/role in PC teams</p> <p>Profile piece/anecdotal/authors view</p> <p>Supports SLT inclusion</p> <p>Suggests more integration needed</p> <p>Useful overview of intervention</p> <p>Includes rehabilitation conflict and need for training</p>	<p>Discusses ending therapy in Pall care</p> <p>Attempts to define SLT role in PC</p> <p>Uses case studies</p> <p>Includes lack of inclusion in PC teams</p> <p>Supports SLT role in PC</p> <p>Suggests lack of awareness of SLT role</p> <p>Includes rehab conflict</p>	<p>Discusses dysphagia at eol re artificial nutrition/hydration.</p> <p>Authors view of literature</p> <p>Suggests SLTs need specialist skills for eol</p> <p>Discusses issue of identifying when eol occurs</p> <p>Treatment planning</p> <p>Pt led decision making</p> <p>Documenting</p> <p>Risk feeding</p> <p>Supports SLT role</p>

** denotes papers with strongest content related to the research question. Bold type denotes highly relevant content.

Table 3 Detailed analysis and comparison of each of the eight strongest papers of relevance to the research topic.

	Author/date	Pollens 2004	Pollens 2012	Newman 2009	Roe 2007	Roe Leslie Drinnan 2007	Eckman Roe 2005	Roe & Leslie 2010	Levy et al 2004
1	SLT is of value	✓	✓	✓			✓	✓	✓
2	MDT based	✓	✓	✓					
3	eol is within remit								
4	Education needed		✓ **		✓		✓	✓	✓
5	Little evidence	✓			✓		✓		
6	Little inclusion in MDT	✓	✓	✓	✓	✓	✓	✓	
7	few articles re role	✓							
8	Discusses conflict rehab vs. eol	✓	✓		✓ (just)		✓	✓**	
9	Identifies role content	✓	✓	✓				✓	
10	Identifies need for role development	✓	✓		✓	✓	✓	✓	
11	Discusses ethics	✓					✓	✓	
12	Describes increasing AHP involvement	✓							
13	Includes anecdotal cases	✓	✓	✓				✓	
14	support for SLT from outside profession	✓							
15	lack of mention of SLT								
16	communication important		✓	✓					✓

** denotes papers with strongest content related to the research question.

Table 4 Detailed analysis of eight papers primarily but not directly related to the research topic

	Author/date	Salt Davies Wilkinson 1999	Langmore 2009	Mathison et al 2011	Biddle & Mitchell 2008	Toner & Shadden 2012	Groher & Groher 2012	Rivers et al 2009	O'Reilly et al 2015
17	SLT is of value	✓	✓	✓	✓	✓	✓	✓	✓
18	MDT based		✓	✓	✓	✓	✓		✓
19	eol is within remit			✓ not taught					✓
20	Education needed	✓		✓ ed'n pilot	✓	✓	✓**	✓**	✓
21	Little evidence					✓			
22	Little inclusion in MDT	✓							
23	few articles re role					✓			
24	Discusses conflict rehab vs. eol		✓		✓	✓			
25	Identifies role content	✓ (brain CA)	✓		✓		✓		
26	Identifies need for role development	✓		✓	✓	✓			✓
27	Discusses ethics					✓	✓		✓
28	Describes increasing AHP involvement					✓			
29	Includes anecdotal cases		✓				✓		
30	legal discussion					✓ USA			
31	communication impairment		✓	✓			✓		
32	Other professions					✓ OT			

** denotes papers with strongest content related to the research question.

Table 5 Detailed analysis of papers and documents related to Professional Bodies, other professions and other countries

	Prof bodies/ other profs/ countries	ASHA 2007 Ambros i	ASHA 2012	NIC E 200 4	SIGN 2006	GMC 2010	RCP 2010	Keesing 2011 (OT)	Guru 2012 (physio)
33	SLT is of value	√	√	√	√		√		
34	MDT based		√	√	√	√	√	√	√
35	eol is within remit	√	√	√				√	
36	Education needed	√	√				√		
37	Little evidence								
38	Little inclusion in MDT			√				√	√
39	Few articles re role								
40	Discusses conflict rehab vs eol	√	√ differen ce not conflict						√
41	Identifies role content	√					√		
42	Identifies need for role development	√	√					√	
43	Discusses ethics	√	√				√		
44	Describes increasing AHP involvement			√	√				
45	Includes anecdotal cases	√					√	√	

Table 6 Detailed analysis of articles and general papers related to other diagnoses and professions

	Other diagnoses articles general papers	Campbell 2010 Article	Ward 2004 article	Cimino 2003 conf summary	Vitale et al 2011	Cinocco 2007	Cline 2006 article	Payne 2011 Letter - Dietetics	Glascott et al 2012 article
46	SLT is of value	✓			✓	not mentioned	✓		
47	MDT based	✓			✓				
48	eol is within remit								
49	Education needed		✓ Ed prog					✓	✓
50	Little evidence								
51	Little inclusion in MDT								
52	few articles re role								
53	Discusses conflict rehab vs. eol			✓ not as such					
54	Identifies role content								
55	Identifies need for role development								
56	Discusses ethics			✓					
57	Describes increasing AHP involvement								
58	Includes anecdotal cases			✓					
59	communication				✓				

Discussion of the influence of the author on literature review design and selection /reflexivity

This author's work as a practising SLT clinician, facilitated the initial search in that key authors were widely known within the profession, which provided a suitable starting point for further exploration. Previous experience of reviewing literature search outcomes for relevance, during a secondment to a research centre, also proved of benefit. This ensured that the process was conducted thoroughly and systematically, with a clear audit trail throughout should there be a need to re-trace any steps.

Literature specifically related to the research question

The following section considers literature related to specific key aspects of the research question including terminology, multi-disciplinary working and education.

Speech and Language Therapy and Palliative Care/end of life care

An attempt to make a distinction between palliative care and end of life care is often made by researchers, with palliative care used to refer to a longer term situation in managing intractable illness and end of life referring to care during the final days or weeks of life (Pollens, 2012, Toner and Shadden, 2012). It is clear however, that there is some variation and inconsistency in the way these terms are used within the literature and across professions. As shown in the introductory chapter, the British Medical Association uses the additional term 'end stage care' to refer to the actual process of dying (GMC, 2016). This apparent inconsistency and ambiguity presents an added challenge in this sensitive area of healthcare. If fellow professionals are unclear about terminology, it does not make for a transparent arena in which to examine the care that is being delivered.

The implications for practice and intervention are likely to differ depending on the perceived timescale towards death. What may be acceptable management on a long term basis, may become less suitable where someone is near the end of life. Toner and Shadden (2012) attempted to set out what SLTs should know about end of life care and suggested that SLTs were not currently adequately prepared for the role. They identified a need to understand the dying process and highlighted a role for SLTs in decision-making, communication and modifying input according to changed status, which would seem a reasonable suggestion. Pollens (2012) discussed palliative and end of life care definitions and principles in relation to how the SLT could modify their contribution to each, using case discussions to demonstrate. This provided a practical approach to considering the topic within the frame of reference used for the terms.

Although the literature specific to SLT is limited, there does appear to be a consensus view that SLT inclusion in palliative and end of life care is of value (Eckman & Roe 2005, Langmore 2009, Levy et al 2004, Mathisen et al 2011, Pollens 2012, Pollens 2004, Roe et al 2007, Roe and Leslie 2010, Salt et al 1999). Since some papers consist mainly of anecdotal case discussions and personal views, it may be anticipated that those produced by SLT professionals would see the role as of value. However, it could be argued that those most equipped to make a credible initial judgement as to the value of SLT input at this stage of care, are SLTs themselves.

In terms of role content, a number of researchers have made significant attempts to clarify what they perceive to be the role of the SLT within palliative and end of life care (Eckman & Roe 2005, Newman 2009, Pollens 2004, Pollens 2012, Salt et al 1999). In general, these papers share the view that SLTs can provide valuable input in terms of support, establishment of baseline functioning and strategies to maintain and maximise function with disease progression.

Speech and language Therapy and Rehabilitation

Rehabilitation is defined as:

'The action of restoring someone to health or normal life through training and therapy after imprisonment, addiction, or illness'. (Oxford Dictionaries, 2016).

'To return someone to a good, healthy, or normal life or condition after they have been in prison, been very ill, etc'. (Cambridge Dictionary, 2016).

Within the context of rehabilitation in palliative care, Doyle et al (2005) in the Oxford textbook of palliative medicine, advocated the four levels of classification of rehabilitation in cancer care by Dietz (1981). This includes preventative, restorative supportive and palliative components.

Within the literature, there has been some tension around the SLT role and the term rehabilitation within the context of palliative and end of life care. There is discussion (or at least a clarification of stance stated) within a number of papers, regarding the use of the term within the end of life setting, when discussing the SLT role. This is perhaps due to the strong historical association between SLT and rehabilitation, thereby leading researchers to feel a need to discuss how SLTs can view their role with this group within the existing professional framework.

This is exemplified by Salt et al (1999) who in an early paper, outlined what SLT involvement could bring to palliative care with brain tumour patients. The authors discussed the limited access these patients had to SLT and attempted to demonstrate how SLTs could contribute in terms of assessment, advice, treatment and training. The authors highlighted the impact SLTs could have in enabling patient participation in decision-making. Since this early paper, SLT involvement in brain tumour care has developed as reported by Langbecker et al (2016) who considered the supportive care needs of forty patients in Australia with brain tumours. They reported a 97% awareness of SLT services amongst patients, although in fact they also noted that only 50% of those with relevant symptoms were actually referred for SLT. This may suggest that

there is still some need for wider recognition and development of the role. It is unclear too, whether these results reflect the current position in other countries.

There is also evidence within current literature and indeed within the author's local service, of SLT intervention at an earlier stage in the care of brain tumour patients, with a current development towards SLT involvement in awake craniotomy procedures. In these cases, SLTs are developing an integral role in conducting language assessments during the awake craniotomy procedure, with the intention that potential deficits arising from the surgical management of brain tumours can be mitigated. This is achieved by using stimuli to mimic the potential effects on language at the site of surgery (De Witte et al, 2015).

One of the key contributors to the debate about SLT involvement in palliative care in HNC is Justin Roe, an SLT at the Royal Marsden Hospital in London, who has discussed the issue of the suitability of the term rehabilitation within palliative and end of life care on a number of occasions and in collaboration with other researchers. Eckman and Roe (2005) discussed what SLTs had to offer in palliative care for people with HNC and concluded that the lack of inclusion of SLTs in palliative care teams, was possibly due to a lack of understanding of what SLTs could bring to this client group (such as contributing to realistic goal setting, ethical decision-making, risk management and assessing/managing dysphagia). This seems a reasonable conclusion in support of the case for SLT contribution to palliative and end of life care. Eckman and Roe (2005) too, suggested a need for SLT education in this field. In a conference presentation, Roe (2007) again discussed the concept of rehabilitation in relation to palliative and end of life care in what appeared to be a further attempt to define and extend the meaning of the term and highlight future directions for research. This related to an apparent sense of tension within the literature regarding the appropriateness of rehabilitation in palliative and end of life care. Roe and Leslie (2010) discussed the view that the term 'rehabilitation' may be unsuitable for some palliative patient groups and attempted to explore the term, to clarify a broader role where functional status was in decline. The authors proposed that the term rehabilitation may be misleading in this context and that 'readaptation' may be a more appropriate term to adopt as it implies

adjustment rather than a return to pre-morbid functioning (Roe and Leslie 2010). The authors presented a strong argument that entering the end of life stage should result in a change of input rather than the cessation of SLT but that SLTs need to learn the appropriate skills to provide this.

A second key contributor to the debate on this topic is Robin Pollens, an American SLT who, in exploring the role of the SLT in palliative care within HNC, suggested that some clinicians may take the view that rehabilitation in end of life care may be inappropriate. She used this as a basis for her view that there is a role but also a need to clarify what that role is (Pollens 2004). In the same publication, Pollens provided a valuable summary of the role in four key areas: consultation, providing strategies, optimising function and communicating with the MDT. Biddle and Mitchell (2008) in describing a palliative SLT post, discussed the need to move away from a traditional rehabilitation emphasis with this client group. Langmore (2009) in outlining management approaches to a number of palliative conditions, made a distinction between rehabilitative and compensatory therapy.

More recent publications have moved towards exploring what the SLT role is with increasingly less emphasis on the previous sense of tension with a 'rehabilitation based' profession. In a later paper, Pollens (2012) again raised the issue of clarity of role within the rehabilitation versus palliative environment within HNC. In this paper, Pollens appeared to have resolved the issue to some extent in her urge to encourage SLTs to be proactive in integrating with the palliative care team and promoting the role. Toner and Shadden (2012), provided an overview of end of life SLT care for people with HNC and accepted, clarified and defined the role in agreement with Pollens (2012), whilst still acknowledging that it may not have been traditionally associated with the SLT profession. Groher and Groher (2012) in a discussion of decision-making around non-oral feeding in end of life care, also supported the inclusion of SLTs within the multi-disciplinary team. Buck (2013) in exploring end of life care issues regarding non-oral feeding in a professional magazine article, also supported the role of SLTs in end of life care and made a further attempt to clarify what that role was, broadly supporting previous studies. A document outlining the role of AHPs in cancer care

including palliative care, made the point that more understanding was required of the role of rehabilitation in this area (Macmillan, 2011).

A recent report produced for Hospice UK by Tiberini and Richardson (2015) has a focus on rehabilitative palliative care and recommends that AHPs should be included in palliative care teams and states that palliative care is:

‘..a paradigm which integrates rehabilitation, enablement, self management and self care in the holistic model of palliative care.’ (pp2).

This would certainly seem to embrace the inclusion of rehabilitation into the sphere of palliative care.

Multi-Disciplinary Working

Almost without exception, papers concerning palliative and end of life care roles for SLTs and other AHPs emphasise the multi-disciplinary team working model (Biddle and Mitchell 2008, Groher and Groher 2012, Pollens 2004, Pollens 2012, Toner and Shadden, 2012). However, there is also recognition that currently AHPs are not well represented as core members of most multi-disciplinary palliative care teams (Newman 2009, Pollens 2004, Pollens 2012, Waldron et al 2011). Pollens (2012) observed that SLTs do not usually play a routine role in the typical HNC palliative care team.

It is interesting to note that some studies with a medical focus, fail to include any significant content regarding the contribution which can be made by SLTs (Cinocco 2007, Gillick 2009, Kaldjian 2009, Lin 2011, Sciubba 2009). Javier (2011), in an attempt to discuss the role of rehabilitation in palliative care, supported the view that rehabilitation was indicated and attempted to outline evidence for the involvement of different AHP professions. Unfortunately, Javier (from the medical profession), did not appear to have liaised with those professions, only to have conducted a literature

review seeking randomised control trials and based a brief section on SLT on two studies. This approach somewhat limits the impact of the paper. A broader search of all published evidence, may have resulted in a more representative view of the SLT contribution, outside of the narrow field of randomised control trials alone.

Education

There is strong consensus within the literature regarding the need for education for SLTs, AHPs and other healthcare workers in palliative and end of life care. Whilst there is an emphasis on the need for strong multi-disciplinary team working and decision-making (Biddle and Mitchell 2008, Eckman and Roe 2005, Groher and Groher 2012, Levy et al 2004, Roe and Leslie, 2010, Pollens 2004, Pollens 2012, Toner and Shadden, 2012) it is suggested that the role however, needs to be further defined and developed (Eckman and Roe 2005, Pollens 2004, Pollens 2012, Salt et al 1999). Some researchers discussed the perceived conflict between a rehabilitation based undergraduate training for SLTs and the differing needs of palliative and end of life care patients (Langmore 2009, Pollens 2004, Roe and Leslie 2010).

Australian researchers discussed a pilot approach to educating SLTs in palliative care alongside the existing curriculum and suggested a need for training. They identified a requirement to consider ways of thinking about palliative care and identified four core skills: effective communication, recognition of diversity, principles of assessment and management and reflective practice. The study reported that the pilot approach proved successful but some of the conclusions were not well supported in that numbers of students completing both the pre and post training evaluations were low (one hundred and forty SLP students took part in the training but only twenty-seven completed both evaluation questionnaires). In addition, they did not demonstrate robust evidence for how they concluded that participants fully engaged with the process. In spite of this, the pilot was well constructed in its content and employed a variety of formats to enhance access e.g. self directed learning with a CD rom alongside mentoring and teaching (Mathisen et al 2011).

A further paper identified newly qualified medical staff as feeling unprepared for palliative care work and attempted to address this via implementation of hospice placements within medical training (Glascott et al 2012).

Literature from the wider context

Other Professions

Guru (2012) discussed the role of physiotherapy attempting to clarify the difference between rehabilitation and palliation in head and neck cancer and suggested that rehabilitation was indicated throughout the patients care journey to prevent, restore, maintain or support. Payne (2011) discussed palliative care education options for dietitians and sought to highlight a view that dietetic palliative care is under-accessed. Keesing and Rosenwax (2011) conducted a qualitative study aiming to establish the current level of professional involvement and the needs of palliative patients, from an Occupational Therapy perspective in Australia. They identified a lack of resources and a need for education regarding the role.

Other Diagnoses

The role of SLTs in palliative and end of life care teams has received a fuller consideration for some diagnoses than for head and neck cancer. Vitale (2011) considered how SLTs and medical staff could work closely together to manage dysphagia in the dementia patient. Waldron et al (2011) highlighted the significant role of AHPs in the management of symptom relief in Parkinsonism and commented on the difficulties around a lack of AHP education and the term 'rehabilitation'.

Other Countries

The literature outside the UK for SLTs working in HNC, shows an encouraging development towards wider recognition of SLTs as core members of the palliative care team. There are attempts to address the need for education in Australia (Mathisen et al 2011) and to outline the SLT facilitative, compensatory and ethical roles in the USA (ASHA, 2012).

National and Guidance Documents in the UK

In the UK, to date, the RCSLT professional standards, clinical guidelines and position papers contain sparse information on palliative and end of life care and lack clear guidance (RCSLT 2005, 2006). Other documents such as the RCSLT commissioning papers refer to the role of SLTs in relation to service funding but do not offer comprehensive support (RCSLT 2009). National documents relating to improving outcomes in HNC and improving the end of life experience refer to SLT but do not offer professional guidance (NICE 2004, SIGN 2006, Scottish Government 2008). More recently, there is evidence that this is changing with the work of the National Cancer Action Team in particular (NCAT 2009, 2012, 2013) which is producing valuable documents supporting the role of AHPs including SLTs, in palliative care. The RCSLT too is now addressing palliative care within the profession in its ongoing development of online resources (RCSLT, 2016).

Ethical Considerations in SLT

The literature concerning the role of SLTs in palliative care discusses ethical issues and dilemmas. A significant contribution to this debate has been made by Pollens (2004) who suggested using ethical principles as a guide, when planning clinical interventions or managing changed status. She used the example of non-oral feeding, which may initially be seen as helpful, but may become a challenge, should the person

later wish to eat and drink nearer the end of life. In this situation the ethical principles of informed consent and autonomy would then come to the fore.

Anecdotal case discussion within other literature suggests that some difficulty arises in that SLTs are not fully represented within palliative care multi-disciplinary teams and may not therefore have the recognition or professional support that this would provide (Newman 2009, Pollens, 2004). In the UK, it appears that no survey has been conducted to verify this view so we remain unclear about how many SLTs are part of palliative care teams. This would be a pertinent topic for future research.

What the literature broadly concludes

In summary, there has been minimal exploration of what clinicians' experiences are within this area of practice and what has been done is confined mainly to the use of anecdotal case discussions, in an apparent attempt to clarify the role and contribution of the profession to this stage of care (Groher and Groher 2012, Newman 2009, Pollens 2004, Pollens 2012, Roe and Leslie 2010).

In the context of an ageing population (ONS, 2015) it is likely that end of life care, not confined to the HNC population, will become an increasing aspect of the role of all healthcare professionals. Therefore this research may ultimately have some relevance to a wider group than that of the initial focus.

Overall there is broad consensus that SLTs can have a valuable role in enabling effective participation in ethical decision-making/goal setting around eating and drinking and assessing and managing the associated, changing risks (e.g. providing strategies to minimise aspiration by altering food textures, swallowing technique, bolus size or head posture etc). This role is presented as enhancing quality of life for patients and enabling a sense of continued involvement for carers. There is also an emphasis on the need for SLTs to have multi-disciplinary involvement and communication with the care team and to develop additional skills for practicing in this area (such as an understanding of the dying process, ethical principles and the roles of other members of the MDT).

A developing core of SLT specific UK publications reveals a sense that the topic of SLT and indeed AHP involvement in end of life care is gaining some momentum. There are increasing attempts to clarify the role both in the UK, outside the UK and from other professions. There is however a paucity of SLT inclusion in UK national documents on palliative and end of life care currently and there remains a need to further explore the SLT role in this area. This is particularly relevant, given the debate about whether rehabilitation indeed has a role in end of life care. Key aspects of the SLT role that can be drawn from the literature include a contribution to informed ethical decision-making and participation, multi-disciplinary communication, goal setting and dysphagia risk management. Overall there is agreement that SLTs can provide valuable input in terms of support, establishment of baseline functioning and strategies to maintain and maximise function but that education is required in order to do this effectively.

To summarise, the literature demonstrated a predominance of anecdotal or case study material with few examples of higher levels of evidence such as randomised control trials specific to the topic of interest. This may be a reflection of the nature of the topic since an examination into the experiences of palliative care may lend itself more to a case study or qualitative approach. There was recognition within the literature of educational needs, a need for guidelines and professional frameworks, however, this was not generally presented as the main focus with most reference being made to clarifying the nature of the role. The literature review confirmed key issues for the profession and added a new dimension related to the position for other professions and other countries which supported the argument for the need for this research since the same issues were encountered across a wide body of literature.

The next chapter will consider the approach taken towards identifying an appropriate methodology to answer the research question.

3 Methodology

The research question asked:

What experiences do SLTs have of preparing for and delivering end of life dysphagia care with adult HNC patients and what do they think is needed to provide it effectively?

Identifying the best fit methodology for the question

Having identified the research question the next phase of preparation was to investigate the most appropriate methodologies to consider, in order to answer the question effectively. The author's previous study of quantitative and qualitative research methodologies provided a foundation knowledge from which to begin.

Quantitative versus qualitative

As outlined previously in the section on personal stance (pp17), the type of research question and the manner in which it is asked, can determine the researcher's choice of whether to adopt a quantitative, qualitative or mixed methods approach. The researcher is required to consider the most suitable fit to answer the research question effectively (Crotty, 1998, Silverman, 2010).

Broadly, a quantitative approach is most suited to questions seeking to establish data regarding numbers, frequencies or patterns of occurrence whereas a qualitative approach is most suited to questions seeking to answer questions relating to exploring human experiences, meanings or interactions (Hennink et al, 2011).

Qualitative research method selection

Having identified an affiliation with an interpretative stance (1.3.1) and as the research question involved examining the lived experiences of people, a qualitative methodology

was deemed to be appropriate. The field of qualitative methodology is complex, evolving and widely variable (Pope & Mays 2006). An initial exploration of frequently used qualitative methodologies was the starting point.

Ethnography

Ethnography is a term which has its origins in social research and concerns the study of communities of people. The ethnographic researcher seeks to live amongst the people of interest and observe and record in detail all aspects of life, from the perspective of those living within the culture. Ethnographers may also seek to identify generalisable features which can be applied outside of the studied group. Conducting a robust ethnographic study, may require some considerable time to be spent in which to fully immerse the researcher into the environment i.e. time spent 'in the field' (Denscombe, 2010). Although an ethnographic approach could certainly have been usefully taken with this research question, it was felt that in order to conduct a strong, ethnographic study, the time and detail required would have been too great alongside a demanding senior healthcare role.

Phenomenology

The origins of phenomenology as a philosophical movement, stem predominantly from Germany and France in the early part of the twentieth century (Bowling, 2009). Phenomenology is concerned with how individuals perceive and experience what appears before them i.e. how the world is experienced via human consciousness within naturally occurring settings – the lived experience (Sokolowski, 2000).

The Austrian philosopher Edmund Husserl (1859-1938), working in Germany, presented the world with his notion of phenomenology as a philosophical movement, rejecting the dominant positivist view and suggesting that the natural sciences experimental focus had not fully considered the individual. Influenced by the previous work of the German philosopher Franz Brentano (1838-1917), Husserl was interested

in consciousness and developed Brentano's suggestion that consciousness is always focussed on an object. This is termed intentionality and is central to the core ideas of Husserl's phenomenology (Moran, 2000).

Husserl proposed that in order to examine consciousness, it was necessary to bracket out pre-conceived ideas in order to view the object with an open, focussed, mind rather than through the accepted or known meaning associated with the object in society. In doing so, Husserl asserted that this process could result in new meaning shedding light on the essence of the experience for the individual and others. (Smith, Flowers & Larkin, 2009).

Husserl's pupil, philosopher Martin Heidegger (1889-1976) moved away from the idea of consciousness to consider the sense of being. Heidegger considered how the individual existed, which he viewed as intertwined within the context of the world and the past and present (Finlay, 2011). Heidegger also explored the notion of interpretation and suggested that interpretation occurs throughout all aspects of existence thereby questioning the goal of viewing an object with an open mind (Moran, 2000).

The French philosopher Maurice Merleau-Ponty (1908-1961) aligned with Heidegger in a desire to consider context and interpretation as well as the individual nature of how experiences are interpreted (Smith, Flowers & Larkin, 2009).

Hans-Georg Gadamer (1900- 2002) was a German philosopher, who explored human understanding and suggested the view that all understanding stems from symbolic language and communication within a social context. Gadamer suggested that in order to gain new understanding, it is necessary to move away from one's own 'horizon' or personal world view (Finlay, 2011). Gadamer explored the idea of hermeneutics, in essence, that interpretation occurs inherently to some degree in all interactions.

It would seem then, that setting differences aside in terms of philosophical stance and focus, phenomenology as a whole concerns an exploration of what it is like to experience a phenomena and what that means to an individual in the context of their natural, everyday existence.

Moving on from the origins of the philosophical branch of phenomenology, the application of phenomenological principles to research will now be considered.

Phenomenological approaches to research

Phenomenological research seeks to apply philosophical principles in order to undertake a detailed and in depth examination of conscious experiences, as reported by participants. It concerns attempting to set aside any researcher pre-judgement, in order to explore the reported lived experience of a group of individuals around a designated topic. The purpose is to examine the participants responses to phenomena consciously experienced, naturally within everyday life. The researcher aims to reveal a common essence or truth of that encounter shared by participants, thereby enhancing the overall understanding of the designated topic (Cresswell, 2013).

Interpretative phenomenological analysis - IPA (Smith et al, 2009).

This specific, structured but still flexible approach to conducting phenomenological research, was developed by Jonathan Smith in 1996 and has become a popular approach in psychology and the social sciences (Finlay, 2011). IPA research seeks to gain a detailed, in depth view, of an individual's reported experiences thereby gaining insight into their lived experience. IPA research resonates with Gadamer's hermeneutic discussion in that it adopts an interpretative aspect in an attempt to reveal the meaning attributed by participants to their experiences. The impact of the 'double hermeneutic' is inherent in IPA research. This term describes the act of the individual interpreting their experience and the researcher attempting to interpret the reported experience of the individual (Smith et al, 2009). This could be likened to a confounding variable in quantitative research, in that it presents the possibility for misinterpretation as a result of the unintended influence of the researcher's own perceptions and experiences on the process.

IPA is an idiographic process as it focuses in detail on what sense participants make of their particular experiences at an individual level, before attempting to reveal the

shared essence of the experience (Finlay, 2011). The IPA process typically consists of small purposeful samples (usually under ten) with participants selected according to their exposure to the criteria under investigation. Data is typically generated via audio recording of semi-structured interviews (Smith et al, 2009). Following data generation, each individual interview is transcribed verbatim, including any hesitations, repetitions, errors and all researcher utterances (Finlay, 2011). Each transcript is then reviewed in detail repeatedly to identify any emerging themes, points of interest, incongruencies etc with informal notes and comments added to the text. Once all transcripts have been through this lengthy process, the researcher then attempts to review the data as a whole, for all participants together. This process reveals emerging and ultimately overarching or super-ordinate themes as well as any potentially apparent anomalies across the data, which would require further exploration (Smith et al, 2009). In subsequently preparing the findings as a text, excerpts from the verbatim transcripts are used to exemplify the resultant themes. The intention in doing so, is that this will retain authenticity and accuracy by referring directly to the generated material and keeping the interpretation transparent and clearly rooted with the participants.

In considering the nature of the research question seeking to explore individual experiences of participants within a specific, sensitive situation, it was felt that an IPA approach would be suited to the topic of interest. The researcher would be able to conduct a robust, smaller scale study which would allow appropriate opportunity for participant detail and depth of analysis by employing an interpretative phenomenological analysis (IPA) approach.

On closer examination, however, one aspect of this approach appeared to be problematic. Namely the concept of 'bracketing' out the researcher's own preconceived ideas. It would seem somewhat contradictory to accept that data is generated collaboratively as a result of social interaction whilst at the same time attempting to identify and remove the researcher's own perspective, in order to be open to that of others (Smith et al 2009). Although on reading into this topic, it became clear that the researcher is not asked to remove all presence from the research and is in fact asked to be reflexive and to acknowledge their influence, there still remains some question about how an approach with its foundations in transparency and shared experience,

can accept any methodology that requires any degree of self censorship as such. There is also recognition within IPA, that the researcher cannot gain full insight into the lived experience of participants as another person with a different perspective, however well set aside or 'bracketed' the researcher's views are and that in the end, the output of any such research will inevitably be a co-construction created by both the participant and the researcher (Finlay, 2011)

In employing an IPA approach, however, the researcher would need to attempt to identify, recognise and limit their own influences. At the same time, in so doing, the researcher would be denying one of the fundamental tenets of phenomenology regarding data generation in a natural setting by knowingly modifying their role.

Having explored these issues and the pros and cons of this approach, it was decided that on balance, IPA afforded a clear means of handling the data and the decision was made to employ a broad IPA approach with a focus on adopting acceptance and transparency around the author's participation in the research alongside the participants.

Phases of the research

The research consisted of three phases following preparation of the initial proposal. An initial preparatory and pilot phase, the main participant data generation and evaluation phase and the final write up phase.

Planning and Timings

The original outline research proposal was accepted in June 2013. At this point, the focus was then placed on gaining appropriate permissions and approvals, in order to allow data generation to commence in August 2013. Preparatory work had been undertaken from April 2013, in the form of the researcher familiarising with requirements and undertaking introductory online training in the completion of IRAS forms. Informal discussions with local Research and Development support staff were also undertaken at this time. Data generation was completed by the end of August

2013 and transcription and member checking by December 2013. Member checking refers to the agreement between researcher and participant, that the individual's interview transcript will be shared with them on completion. In this case, it was agreed that the prepared transcript would be sent to participants before any analysis took place. The intention was to allow participants to read their own transcript and to have the opportunity to highlight any areas they viewed as inaccurate. Miles and Huberman (1994) point out that although this type of approach can help to inform the accuracy of the transcription process, it can result in difficulties should the participant seek to have aspects of the transcript removed or changed. As it turned out there were no requested changes.

Data evaluation began to evolve alongside the early transcription process and preparation of the initial, broad writing plan. This allowed themes to begin to emerge from the generated material at the outset, in an iterative process and facilitated familiarity with the data from the beginning. IPA research requires that the researcher becomes immersed within the data, gaining familiarity with it and retaining a close involvement with all material generated throughout. This process begins at the time of the interview and continues during transcription, when observations can occur at any time. IPA is therefore an iterative process, developing and changing along the way (Finlay, 2011).

Constraints (workplace)

Workplace issues included reduced staffing, which resulted in some delays in the data generation phase in order to prioritise the researcher and participants workplace roles.. In addition, the author's senior role required involvement in one of the biggest change management issues in the Scottish NHS, related to the consolidation of several hospitals into one new centre, over a relatively short period of time. This had a significant impact on study timescales as the emphasis at this time was on staff engagement and support throughout such a challenging process.

Preparatory work

This section outlines what preparatory work was undertaken in advance of the study commencing, including gaining relevant permissions, access and the preparation of research information.

Consents and permissions

April – July 2013

Completion of NHS Research and Development approval forms.

Completion of QMU research outline and ethical approval forms (Appendix pp 221)

Development of research information

An overview of the research had been prepared for the local research and development office. This, along with the original research proposal, formed the basis of the participant and line manager research information document. A copy of the intended research information was approved by the Research and Development officer prior to any approach regarding access being made (Appendix pp 204).

Negotiating access

Access approval was required both from line managers of the participating staff and from individual participants. Letters were prepared and approved by the local Research and Development officer, prior to contact being established (Appendix pp 198-215). All line managers were initially contacted directly by telephone, before sending out the formal request for access letter and research information, with a stamped addressed envelope in which to return the signed approval form.

R&D/IRAS/NRS

Contact was established with one of the health board Research and Development Officers in September 2012 and an outline of the proposed study provided. As the study involved staff rather than patients, the Research and Development officer confirmed that NHS ethical approval was not necessary but that an IRAS application was required. An IRAS application was prepared and approved prior to commencement of recruitment and data collection. In addition, NRS approval was also gained due to the multi-centre design (Appendix pp 215-220).

Managed Clinical Network for HNC (MCN)

As the focus group comprised of members of the West of Scotland MCN for HNC, the MCN lead had been made aware of the project and confirmed that it did not require further MCN consent.

Impartial Research Contact

A senior member of the local nursing staff with a lead role in palliative care, was recruited as an impartial research contact and was available to all participants and line managers if required. This was to ensure that all participants and their relevant line managers were able to access an impartial contact, should they have concerns or wish to discuss any aspect of the research process at any time. It was felt that this was a necessary step in view of the sensitive nature of the research question.

Discussions were held with staff in leading roles within undergraduate and post-graduate education of SLTs, regarding the project idea and relevance. A meeting was held with a local University SLT lecturer regarding the research topic and its relevance to the higher education syllabus. This was conducted on an opportunistic basis following an existing meeting regarding service issues. Discussions were also held with a completing PhD student with a similar professional background in order to discuss the research question and selection of an appropriate methodology. This was of

particular benefit, in that it allowed the researcher to gain an understanding of the demands of conducting a qualitative study and to discuss options and resources.

Telephone discussions were held with a leading researcher who had published papers on HNC and palliative care regarding topic viability and current relevance. This allowed the researcher to explore the viability and relevance of the research question, in the context of a current expert in the field.

Ethics Planning

Contact was established with one of the health board Research and Development Officers and an outline of the proposed study provided. There was recognition that the topic of the research question involved a sensitive area which could impact on participants and the researcher.

Consent was required both from site leads of the participating staff and from individual participants. As the focus group comprised of members of the West of Scotland MCN for HNC, the MCN lead had been made aware of the project and did not require further ethical consent. The researcher liaised with the Research and Development officer re multi-site access requirements.

As all key participants were already experienced, practising clinicians and most had extensive experience within the field of head and neck cancer, it was anticipated that they would have encountered these topics previously within their practice which may have lessened the likelihood of a negative impact of participation in this research. In addition, all local NHS SLT staff (including the researcher) participated in peer support activities within the workplace, which provided a forum for addressing any issues which could arise. These activities were facilitated by other staff rather than the researcher, providing an impartial support. The focus group participants, as part of an existing wider professional group specialising in this area, had access to peer support from within the group. The less experienced pilot participants were also staff working with

head and neck cancer and worked within an existing additional professional supervision framework within the workplace. This provided an opportunity to explore any impact within a supported environment. It was considered that the opportunity to discuss and voice any issues related to the question, may in fact have been beneficial in terms of providing the chance to share experiences with a fellow colleague and may also have contributed to team cohesion as the researcher was a local team lead. Ethical approval was gained from QMU via completion of the QMU ethical approval request form and discussion with the supervisors of the study but was not required by the participating Health Boards.

Confidentiality

The author made contact with the local NHS IT security manager, to establish a method of making audio recordings directly onto an existing workplace encrypted laptop. This facilitated a secure method of retaining interview recordings and maintaining subject confidentiality, according to NHS policy. This method, approved by the IT security manager, involved the use of 'Audacity' sound recording software which was available free on the internet (Audacity, sourceforge.net) and combining its use with an external microphone (Snowball, bluemic.com). This was downloaded onto the encrypted laptop by NHS IT staff in preparation for data collection.

All identifiable audio data was anonymised, coded and stored only on the encrypted laptop. Access was available only to the researcher and supervisory team. It was agreed that all data would be deleted on completion of the study in discussion with the supervisory team.

Research Diary

The decision was taken to implement a research diary. The purpose of this was to provide a means of recording and reflecting on the data collection process and indeed the progress of the project as a whole. This proved to be an invaluable resource in the analysis phase, when the detailed entries served to clarify aspects of the research

context and environment which were not always evident from the recordings or transcripts alone. This therefore added to the richness of the resulting data.

Research interview development

Using interviews

Some exploration of the use of interviews in qualitative research was required. This initially involved reading multiple qualitative studies and published materials concerning the nature of interviews. It was recognised that there were inherent difficulties in using interviews, particularly for a novice researcher. The skills required in attending closely to the participant's responses, whilst also monitoring the timing and accuracy of the process were apparent (Denscombe, 2010).

The researcher therefore practiced interview skills prior to conducting the formal research interviews with people who were not involved in the study. Inclusion of pilot interviews, allowed the researcher to develop and refine interviewing and technical skills as well as providing opportunity for the resultant data to inform the main interviews. In the same way, the focus group was planned to take place prior to the individual, main interviews in order to inform the process further.

Semi-structured

In depth interviews were initially chosen, however, some caution was recognised in that a lack of structure carried the risk of generating data not pertinent to the research question, however interesting. As a result, a semi-structured interview method was selected as it allowed topic prompts towards the direction of the research question, whilst still retaining freedom for participants to speak freely and introduce topics important to them. This approach required the development of an interview schedule in order to guide the topics introduced (Bowling and Ebrahim 2005).

Interview schedule development and limitations

The interview schedule required careful consideration to ensure that it prompted towards the key areas in order to answer the research question but in doing so, did not lead or direct. In addition, there was also a need to ensure that novel topics introduced by participants, could emerge and be examined further within the format. The initial broad literature search conducted in preparation for the research question and proposal, formed the basis of the key topics. These were drawn from the key literature as recurring themes. In addition, further reading around how to prepare an interview schedule was indicated. King and Horrocks (2010) proved a useful guide in highlighting how to design interview schedules within qualitative research, in terms of the type of prompts to include and variety of prompts to employ. The interview schedule was followed in the same order for all participants although some participants ventured onto later topics spontaneously. This was flexibly accommodated within the interview structure.

In addition, there was a requirement to consider how to introduce each interview and what information needed to be given at the outset and on completion (Appendix pp 210). The researcher also took the opportunity to provide self prompts, to ensure that the equipment was ready and that all participants received the same information.

The limitations of this interview schedule were recognised, in that there were a lot of prompts and they were very focused and perhaps not well balanced, with regard to providing opportunity to express positive as well as challenging aspects. However, as the opportunity was given to provide free information, a number of participants did provide positive experiences which it is hoped counters this design limitation somewhat. In addition, some of the prompts were not well phrased, which resulted in some participants requesting clarification. Some concerns were recorded in the research diary regarding this aspect, with reports that some participants required more support and encouragement than others. The diary was also used to record the observation that this resulted in a need to re-phrase and repeat or modify prompts, thereby potentially altering the nature of the ensuing data. However, this is considered to be an appropriate approach within IPA (Smith et al,2009). Reflections also noted a

difficulty in retaining focus on the topic and how to return to it. This did not arise significantly in the pilot or focus group interviews, so was not identified prior to the main participants entering the process. It may have been useful to have requested feedback from the pilot participants on the quality of the interview prompts, in terms of how easy they were to understand. Finally, the researcher's exploratory prompt: 'Would you be able to clarify for me, do you mean..?' had the potential to result in data relating to the researcher's meaning rather than that of the participant. As it turned out this prompt was only used once or twice across the data set, thereby reducing the impact of a potential effect.

Recruitment

The research was confined to the NHS in Scotland, so all participants worked in Scottish Health Boards. As the researcher worked for the largest health board in Scotland with a large specialist SLT HNC service, it was felt that it would be sensible to include local staff in the study, in spite of the fact the researcher is a senior colleague in the local service. In an attempt to gain a wider picture of SLT experiences outside the local health board, staff from three other health boards were also included within the focus group.

Purposive sampling was considered most appropriate, due to the specialist and specific nature of the research question i.e. in seeking to explore the experiences of practicing HNC SLT clinicians (Smith et al 2009). It was felt that the richest data would be gained by utilising this method since the clinical area was small with few staff engaged in this field, therefore requiring the researcher to select appropriately experienced participants. This aligns with Smith's outline of IPA, where it is recognised that there can be a necessity to use purposive sampling where participant numbers are low, in order to access the most appropriate people to answer the research question effectively (Smith et al 2009).

The researcher was also team lead for some of the participants. This was considered to be potentially both a possible asset and a challenge. The selection of participants

and pilot participants from the researcher's team was considered with care. The inclusion of predominantly experienced practitioners (i.e. staff with at least eight years experience of working as an SLT with HNC as a key aspect or component of their role) was chosen in order to access rich data as a result of extensive experience but also to offset any impact of the team leader conducting the research. Until recently, ten of the participants had an existing co-colleague relationship with the researcher and were not in a supervisory relationship. Later, following a period of organisational change, six participants came into the researcher's team and four remained in other health boards. The remaining two, who had been line managed by the researcher for a number of years, also worked alongside the researcher as colleagues on a daily basis clinically. It was hoped therefore, that the peer relationship would take precedence over any reluctance to reveal information which could have been perceived as negative in terms of role seniority. The existing peer relationship with participants could in fact have facilitated discussion in that participants were aware that the researcher had knowledge of the clinical field. It was hoped that the anonymous nature of interview data should also have minimised the effect of the researcher's line management position, on what information was volunteered. However, it was viewed that the benefits of the researcher as a member of the group may also have facilitated the depth and detail of responses.

Demographics of participants

All participants were given the opportunity to volunteer basic, non-identifiable demographic information. This was gathered prior to the commencement of each interview and included the following:

Male/Female

Full Time/Part Time

What caseload does your current post involve?

In what setting do you mainly work?

How long have you been qualified as an SLT?

How long have you been working in HNC?

Ultimately, what transpired, was that some staff did not meet the original criteria with regard to number of years working in HNC but this information was not available at the time of selection. As a result, some participants had significantly less experience in the field but it was felt that their inclusion may in fact, provide a different perspective on the issues under investigation.

All participants were female. At the time of recruitment to the study, no male SLTs were specialising in HNC within the region, so it would not have been possible to gain a mixed gender sample. These minor deviations were discussed and approved by the Research and Development staff overseeing the study.

Table 7: Demographics, Current Post, Setting and Level of Experience (*medical, surgical and associated specialities)

	P1	P2	FG A	FG B	FG C	M1	M2	M3	M4	M5	M6
Gender	F	F	F	F	F	F	F	F	F	F	F
Setting	Acute	Acute	Acute	Acute	Acute	Acute	Acute IP	Acute	Hospital	Acute	Acute
	IP	IP	IP	IP	IP	IP	OP	IP	oncology setting	IP	IP
	OP	OP	OP	OP	OP	OP		OP		OP	OP
Main role	*MSAS sessions	HNC team	HNC ENT Voice	HNC Voice ENT	HNC ENT Voice	Speech Swallow Oncology	Senior SLT DGH, All IPs, HNC Ops Voice Ops	Senior SLT HNC Acute Hospital IP	Senior SLT Broad oncology Mainly HNC	Senior SLT DGH Voice HNC pre, during post treatment	Senior SLT HNC IP,OP Plastic
HNC role	2 x HNC session	HNC Key	HNC Key	HNC Key	HNC Key	HNC Part	HNC Part	HNC Key	HNC Part	HNC Part	HNC Key
Caseload	mixed	HNC	mixed	mixed	mixed	mixed	mixed	mixed	mixed	mixed	mixed
Yrs qualified	5	11	17	30	16	13	19	16	16	30	28
Yrs in HNC	10 months	11 (4 yrs FT HNC)	12	10	8	5	16	13	10	15	24

Letters to participants

On confirmation of line manager approval, the researcher made personal contact with potential participants to invite them to take part in the study. Letters were then issued, inviting staff to participate. A copy of the research information and consent letter was included along with a stamped addressed envelope to enable staff to reply should they wish to take part (Appendix pp 202-209).

Pilot Work

The following section explains the approach taken to conducting pilot work prior to the commencement of the main study.

Pilot interviews (12/8/13 and 15/8/13)

One to one interviews were conducted with two specialising staff from the local NHS service (i.e. staff employed within a post where the focus was on providing opportunity to develop specialist clinical skills). Each interview was of forty-five to sixty minutes duration. It was felt that this would allow time to include all interview prompts as well as providing sufficient time for participants to introduce any additional topics, without resulting in a quantity of material that may become too onerous to handle in the time available (Smith et al 2009). Completion of trial transcriptions had highlighted a need to consider such issues within the main interviews. These staff were also part of the HNC team, with experience of this area of practice within their clinical role. The rationale for including these staff in the pilot was to explore their general experiences and to inform the one to one interview topics. The use of pilot data also allowed the researcher to estimate time required for data transcription as well as allowing the opportunity to develop and refine skills in coding and analysis, with a smaller subset of data prior to the final data collection process. Consent was gained from the local NHS Clinical Services Manager for SLT. Individual information and consent forms for participants were also prepared.

The researcher agreed to interview the pilot participants within their place of work, at a time suitable to them in order to avoid undue impact on the workplace. Both interviews were held in an acute setting, in a quiet room. Some initial technical difficulties were experienced with the recording system in both interviews in that the external microphone did not function however fortunately, the laptop internal microphone provided a high level recording for the Audacity software to pick up. This issue was later resolved, as it was due to researcher error in the set up procedure. In addition, the laptop entered sleep mode at one point during the second interview due to the fact that the researcher had not been watching the recording screen. This was quickly resolved but did interrupt the interview briefly. During the same interview the mains plug became displaced but as the laptop was fully charged this did not disrupt the data collection process.

Focus Group (20/8/13)

A focus group of forty-five to sixty minutes duration was then conducted within an NHS acute setting. Four participants were chosen as a purposive sample from the Managed Clinical Network SLT sub-group. This long-standing group, to which the author belonged, was made up of six experienced, specialist, SLT clinicians working in leading HNC roles across Scotland. As the author was a member of the group along with another member of the local HNC team (who participated in the one to one interviews), only four members were invited for the focus group discussion, with the researcher acting in a facilitatory role. One participant was unable to attend. In spite of this, the group consisted of three members of staff with representation from three additional health boards.

The group was a pre-existing group which normally had a role in contributing to national documents, care pathways and audit. Data generation was arranged alongside an existing meeting to minimise impact on lost working time. The group were aware that the research concerned end of life dysphagia care in HNC and all had consented to taking part in a focus group process.

It was anticipated that selection of this group as a focus group, may have facilitated a more naturalistic opportunity and perhaps more relaxed interaction and discussion of experiences, since the members had an existing trusting relationship with one another. Equally, the level of experience within the group may have allowed access to some specific issues which may not have been revealed by interviewing less experienced staff. Inclusion of this group required access permission from both the members and their relevant line management/health boards. This was achieved via letter and individual information packs and consent forms. An issue arose in that the laptop was not plugged into the mains during this interview but as the battery was fully charged, this did not interrupt the process.

One to one semi-structured interviews (23/8/13 to 30/8/13)

All pilot and main participants were required to have had clinical involvement with HNC patients at this stage of care within their usual clinical role. All main participants had experience of dealing with at least six previous cases where treatment options had become limited or where patients had entered an end stage care situation, as agreed by the multi-disciplinary team.

The six main interviews were conducted in an acute setting. Interviews were of forty-five to sixty minutes duration. It was not always possible to achieve a quiet location but in general, the settings were adequate for data generation. Some inevitable intrusions occurred, some of which were avoidable (such as pagers sounding and telephones ringing) and others unexpected (such as traffic/construction noise and a power surge during interview six, which resulted in having to restart the equipment and make notes to avoid interrupting the flow of the interview). Overall, the interviews were conducted without any major issues.

Data Collection

Equipment

Once the recording software had been downloaded onto the laptop, the researcher was able to source an external high quality microphone (Snowball, bluemic.com) and begin working with the recording system prior to the interviews. This provided an opportunity to become familiar with the set up and to establish how well it would meet the requirements of the project. Several trial recordings were made, which did not demonstrate any obvious issues with the equipment or software.

Records/notes

A decision was made to make informal rough notes at the time of each interview and immediately after completion. This included immediate comments, as well as any participant comments made after the interview (included with the verbal consent of the participant gained at the time). In addition, the researcher then completed a reflective blog (in addition to the research diary) as soon as possible after each interview, where general reflections, practical planning issues and any unexpected occurrences were recorded. This proved to be of assistance in identifying how to manage the differing needs of participants, without knowingly compromising the integrity of the process. The notes did not contain identifiable information.

Settings/timings

All interviews were planned in advance and scheduled to ensure minimal impact on the workplace. Local staff were interviewed at their usual place of work, at a time suitable to them.

The researcher's line manager was supportive of time being allowed to conduct the interviews particularly as the research topic related directly to the local service strategy. All interviews were scheduled across one month, starting with the two pilot interviews then the focus group and finally the six main participant interviews. This format allowed the researcher to make use of information gained from the pilot and focus groups when conducting the main participant interviews (e.g. modification of prompt phrasing,

inclusion of participant topics introduced in the former interviews and development of expertise with the technical equipment).

Transcription Phase

This section outlines the specific aspects of the transcription phase including preparation, planning and what approach was taken to ensure the maintenance of transcription accuracy and integrity.

Preparation and planning

Prior to commencing the transcriptions, some time was spent reviewing methods of qualitative interview transcription. It was decided that the most effective method for the quantity of data, would be a simple system. A template was prepared which included basic, anonymous participant information at the top of the transcript, page numbers, line numbers and a simple use of bold text for participant utterances and regular text for the researcher utterances. In addition, provision was made for contextual comments within square brackets to provide additional information. It was recognised that this would need to be completed with some caution, to ensure that interpretation did not occur when adding contextual comments.

Interview anonymity

Identifiable information regarding participants was retained on the encrypted laptop. All other data was handled in an anonymised form. This involved assigning a code to each participant and ensuring that no identifiable information would be included in the transcripts. Participants were coded anonymously according to whether they were a pilot (P1, P2), focus group (FG A, B and C) or main participant (M1 - 6).

Trial transcription to establish timings

Transcription of the pilot interviews was intended to fulfill a multiple of functions. This included the researcher learning how to conduct the process, as well as providing the means to establish a method of gauging the required timings for the subsequent focus group and main participant transcriptions.

Transcription Integrity

In order to maximise transcription integrity, it was decided that each transcription would be prepared across several short intense periods of time, rather than in one session. This was intended to avoid researcher fatigue and to prevent a loss of concentration which may have resulted in errors. Additionally, the intention was that at the outset of each session, the researcher would need to re-listen to the preceding part of the recording which may serve the added role of facilitating data familiarity and aid with error checking. Member checking was also included, involving a copy of the transcript being provided to all individual participants along with a copy of the original, signed consent form and a covering letter. This letter invited participants to contact the researcher with any amendments or alterations by a specified date. It was decided that member checking would not be instigated for the focus group. The rationale for this decision was that the focus group, being a shared communication event, may not be suitable for individual member checking since each participant would be likely to have developed their own meaning of what had been said. An attempt to then group differing perceptions of the same text, may have proved to be an unreliable method of checking the accuracy of the text, since no one participants view could be held to represent more strength than another. In addition, the fact that the data was generated in a social context amongst a group, may have meant that it should also be member checked as a group which would have impacted on working time in order to arrange a further meeting.

Data Analysis

Smith (2010) suggested how data analysis might be approached within an IPA study. IPA analysis allows for the exploration of data in terms of key themes. The intention is that data is generated and then transcribed verbatim and in detail. In addition, research diary notes, demographic information and records, contribute to the process of gaining a detailed sense of the data. This provides additional information regarding the context and environment in which data is generated. All data is named and catalogued anonymously before analysis, in order to maintain transparency and ease of recall of specific elements of the data. On completion of this task, the focus then shifts to identification of key themes. This process reveals super-ordinate and sub-themes, as well as relationships within the data. Reflexivity is paramount throughout the data collection and analysis phase and requires review and revisiting of the original data throughout, to identify the impact of the researcher on the process.

Although the pilot interviews were initially set up in order for the researcher to practice interviewing, transcription and analysis skills, it quickly became apparent that they had resulted in some interesting findings. As a result a decision was made to include pilot data within the process (Appendix, pp 180-192).

Timing and preparation

Initial timings had allowed a three month period in which to conduct the analysis but this was later regarded as overly optimistic. In part, due to the stated workplace constraints but also due to the novice status of the researcher, which resulted in additional time being required in order to become familiar with the process. The final process took around five months.

Methods of recording

At the outset, data analysis planning had involved employing a paper based system with colour coded notes for each participant/theme in order to identify each participant during the process.

The intention was to analyse each individual transcript one by one, before combining the resultant initial themes on completion of the process. It was anticipated that this would allow themes to be revealed as the process progressed.

Iterative process

As the researcher began analysing the initial pilot data, it was decided to make use of Mindmanager software (www.mindjet.com) in order to present the findings in the form of a mind map. This allowed a transparent, visual representation of the data analysis to be prepared. It was regarded as a way of ensuring data handling integrity and validity, since the process and decision-making would be entirely visible to the reader. The facility to expand or collapse 'stems' of the analysis also facilitated in making the data more accessible, in that it was clear to see how the researcher had grouped data and reduced it towards themes. All final data groups for each individual transcript were entered into separate basic maps (see Figure 2 and Figure 3, Appendix pp195-196). Once the main data had been entered, it was then possible to add offshoot nodes in which to place the original constituent data. In this way, it was clear to see how the data had been grouped. In addition, Mindmanager proved to be a valuable approach in checking and refining groupings, as items can readily be moved whilst retaining a clear sense of the overall content. Mind maps can be reduced or expanded according to viewing requirements for example opening up an entire single node or opening all node chains to view the whole data corpus. It is not possible to include the mind maps in the body of this thesis but they can be shared on request. A screen shot of a 'closed' mind map (Figure 2) with a further shot showing some nodes opened (Figure 3) is included in the appendix (pp195-196).

Although time consuming, the process of returning to the data repeatedly during this task proved to be illuminating, in that it allowed the researcher to become highly familiar with the dataset as a whole and the relationships across and within it, in an iterative process. This was valuable in gaining a deeper insight into the participants underlying expression of meanings.

With the more detailed transcripts, this proved to be a more difficult approach and in these cases, there was a requirement to reduce and synthesise the data somewhat, prior to entering it into the mind map, to ensure that it remained visually accessible. In spite of this requirement, the system still proved to be a highly transparent method of demonstrating how the initial data had been handled.

The researcher considered use of qualitative analysis software such as NViVO (www.qsinternational.com). A decision was taken not to employ such a system. This was in part due to time constraints and access to training but also to a desire to conduct the process by hand, as a learning opportunity for the novice researcher. The use of electronic data handling systems is something which the researcher would be interested to consider in a later study where time could be allowed to fully employ such software effectively.

Table 8: Data analysis process.

Process: individual interviews	Transcription in full with contextual comments
	Anonymise text –removal of identifiable features
	Re-listening to interviews , familiarisation and error checking
	Member checking of text by individual participants (not done for focus group). Transcripts issued to participants with thank-you letter, copy of signed consent form and return date.
	Highlighting of key text with line numbers (initial coding)
	Preparation of new document showing selected text
	Research diary/blog records of process, observations and initial thoughts during process including why excerpts were selected
	Grouping of data for each transcript in turn, utilising mind map format i.e. grouping similar selected phrases under one title within a mind map.
	Pilot interview texts reduced more at this stage than later complex texts – iterative process
	Revision of groupings within mindmap – moving selected text around to find best fit and identify or modify groups
	Detailed description of how groups were created and intended definition of each theme - blog
	Review of groups against original text
	Review of how groups fit with research question – do they answer the question?
	Review of interview notes and blog entries completed at time of interview to seek additional contextual information
	Preparation of word document format as additional way of viewing data
	Word frequency count using 'Text fixer' for each interview from selected text.
	Review of each interview – listening again and gaining sense of data corpus
Process: all interviews	Combining all interviews to identify themes across the data – paper process
	All interview data combined in word document.
	Text electronically colour coded to enable participant identification
	Aspects of data not directly related to research question identified but not excluded
	Repeated review, revision and reduction of data
Process: in-depth	Review of original audio and texts to check for missing data
	Further review of original texts to check whether themes accurately represent data
	Review of similarities, differences and inconsistencies across data
	Review of patterns within each set of data and across the data corpus
	Review of word frequency patterns across data and evaluation of potential influences
	Searching for additional meanings within data – returning to original texts
	Review of data corpus, combining similar topics towards identification of super-ordinate themes
	Blog/research diary notes on general observations during the data analysis process, thoughts about underlying issues and identification/modification process of super-ordinate themes
	Definition of final super-ordinate themes developed from data and from research diary/blog entries.
	Review of final super-ordinate themes in relation to ability to answer research question
	Return to the data as a whole – repeat process of identifying super-ordinate themes from transcripts rather than categories alone.
	Paper texts cut and re-sorted as a whole
	Confirmation of data analysis findings following return to the data process.
	Identification of six super-ordinate themes
	Definition of theme and naming from the most pertinent verbatim data
	Identification of most fitting lens through which to view the data and ensure focus on findings closely related to research question.
	Preparation of findings

Data Analysis Process

This chapter has considered the background to the selection of methodology and the specific methods used with sufficient detail provided to enable the reader to judge the integrity of the study in terms of design and detail. The next chapter will describe the preliminary findings and the ultimate super-ordinate and sub-ordinate themes identified.

4 Findings

This chapter considers the overall findings of the research. Initially, preliminary findings are presented, followed by a detailed description of overall findings following full evaluation of the material generated by participants.



Figure 2 Preliminary Findings

Preliminary Findings

The preliminary findings of the project were presented at the Scottish Partnership for Palliative Care Annual Conference 17/9/14 via poster presentation, a summary of which is depicted above. The full poster is included in the appendix. (Figure 4, Appendix pp 227).

The preliminary findings were based on the outcome of the initial individual and combined data analyses. This was prior to subsequent further, deeper analyses including methods of error checking, such as employing alternative paper methods in a 'triangulation' type approach as a means of comparison. Smith et al (2009) acknowledge that such approaches, present additional demands on the researcher, but can be of value in gaining rich data. This was carried out by conducting a further complete paper analysis, after the use of mindmanager software. Although the broad findings remained much the same, the subsequent detailed examination of the data resulted in a more in depth view of the prominence of key features and relationships within the dataset as a whole. Some inconsistencies and apparent anomalies were identified, including one participant who expressed apparently contradictory experiences regarding multi-disciplinary working (M4). However, on closer examination, this appeared to be a reflection of the participants awareness of the experiences of colleagues rather than a contradiction. Equally, another participant appeared to have expressed views regarding MDT working (P2 in relation to working with consultants) which did not at first appear to resonate fully with the wider data. However, on closer examination, it seemed that this participant was perhaps expressing a more direct view rather than a dissonant view.

Overview of themes

Following the analysis of all data, four super-ordinate themes were identified (see table 9 pp 84). The next section will provide a detailed exploration of the themes. Themes are not presented in any specific order.

Table 9 Super-ordinate and Subordinate themes

Overarching theme	Sub theme 1	Sub theme 2	Sub theme 3	Sub theme 4	Sub theme 5
A risk worth taking	Dysphagia is different Clinical management risks and skills	Safest swallow	Role and type of patient	Patient/carer led decision making	
Under your skin	What it feels like	Impact of setting	Frightened to go into it	Overridden	Support
Communication isn't always wonderful	MDT +ves Part of the team Shared decision making Learning opportunity	MDT challenges Poor awareness Access hierarchies Changing recommendation			
Trained and equipped	Current post, setting and experience On the job external and online learning	Under graduate preparation	Staffing Other demands	MDT communication , profile raising presence	Training needs

Detailed exploration of themes

‘A risk worth taking’

This super-ordinate theme encapsulates how the participants saw dysphagia with this group (as both different and not different), what clinical experiences they recalled, what they did clinically and how they made decisions. This theme also includes examples where risk management had been a significant factor. Risk management was not considered in isolation and therefore comments regarding patient led decision making were also included within this theme as invariably, both aspects were presented as being inextricably linked.

The theme was given the label of ‘a risk worth taking’ from Focus Group comments which seemed to succinctly represent a number of similar quotes within the data relating to patient led risk management decision making:

FGB *‘..we are more aware of patient choices ...it might be that there’s risk of severe aspiration however it’s a risk worth taking for them if that’s agreed that’s the patient choice..’ (752-758)*

Some of the topics discussed in this theme are also further explored in the theme ‘under your skin’ which has a focus on the impact of managing these issues.

Dysphagia is Different – Clinical management, risks and skills

Overall across the data, there appeared to be consensus that the role was highly variable:

M2 *‘....it was unexpected ...originally we thought he had to go into the hospice..for symptom management and he ended up fairly quickly as end of life care...’ (344-349)*

Participants either expressly stated that dysphagia was different with this caseload or went on to explore perceived differences specific to the patient group (P1, FG, M1, M2, M4, M6). Distinguishing factors perceived as making dysphagia different with this

client group included the fact that other factors had to be considered alongside swallow function e.g. pain management, further treatment plans, late onset reactions to previous radiotherapy or unexpected turns of events.

M6 *'..you do often get a completely different set of problems from the one you're predicting so that that can be quite challenging as well ' (726-728)*

Participants frequently referred to clinical management focusing on assessing current status in terms of what disease or treatment had preceded the referral or was anticipated. Conducting a baseline clinical bedside assessment of swallow function was reported with a common aim being to enable the safest possible means of continued oral intake wherever possible.

M4 *'..having a look at their oromotor function..trailing different textures which I would think they might be able to try..safely depending on what they've told me and what I've seen when I've had a look around their mouth...' (412-419)*

'..and then making a judgment based on the bedside assessment as to whether I think they're safe to take anything..' (419-421)

'...so it might mean suggesting ..modifying textures or sticking with foods that are...soft or smooth..or fluids that are just thin or slightly thickened..usually it's thin fluids for this caseload..' (423-428)

Participants were in agreement that there was a need to gather all relevant background, current and planned management information about the referral prior to assessing the patient in order to ensure that the SLT was well informed. The lack of ability to see all patients due to staffing and the time required to support these people was raised. The issue of staffing is also included in the theme 'Trained and Equipped' as participants reflected on what they considered was needed in order to fulfill their role adequately.

M6 *'..we obviously need to be aware of everything that's gone before what is the patient's disease where is the patient's disease what treatments have they had what implications could that treatment possibly have..' (520-523)*

FGA *'..our staffing isn't sufficient to provide a quality service to these patients because of the geography of where I work..' (1350-1355)*

This also seems to impact on the decision making around whether or not to become involved which came up in several interviews and does seem to be a source of anxiety for SLTs. This is explored further in the theme 'Under your skin'.

Safest swallow/the safest possible

The term 'safest swallow' was a phrase which arose from the M4 as well as in similar forms across number of transcripts and was thought to exemplify how the participants viewed their aims.

M4 *'..the way I guess I see our role is pretty much what you would do with any patient ...get a history..what's been happening what's going on..speak to the patient to get their perspective..what they would like.. and then you would assess to see what it is you think you can recommend you know their safest..' (388-399)*

Role and type of Patient

The data suggests that the role includes assessment of the specific nature of the swallowing problem including an assessment of swallowing safety.

M6 *'..taking into account of the whole picture where the patient is, who they're with and what they themselves want which is really, really important..' (536-539)*
'.. try and work out what the risk is where its coming from, what we can do about it and put something in place..' (541-543)

A counseling/supportive/advocacy component is also evident as is a role in raising issues or 'flagging up; new issues, communicating and liaising.

- M2 *'..for me sometimes being an advocate for the patient in the regard to swallowing issues at the end of life..the working as an intermediary sometimes with other disciplines/staff/family..' (485-490)*
- M5 *'..you're not just doing the dysphagia thing but advocating for the patient because maybe you can communicate that better than the patient can..' (516-518)*

The SLTs contribution to education was a common occurrence across the data (P2, FG, M1, M3, M4, M5, M6) . Seeking control for the patient (P1, P2, FG, M1, M3, M4, M5, M6) and preparing the patient for future change was also discussed by many of the participants to varying degrees. (P1, P2, FG, M1, M2, M3, M6),

Exploring and providing guidance around risks and available options and choices came up in many of the interviews. There were several descriptions of how SLTs approached the sensitivities around maintaining comfort and quality of life. Often this was presented as working with the patient to enable them to maintain enjoyment along with the safest swallow (all participants).

- M4 *'..one of the challenges of that is to erm try to educate people that we're not wanting to put people nil by mouth because they're at risk ..' (202-204)*
- (re people not expected to improve) ' ..we're wanting to erm manage them so that they can continue to eat and drink something from a quality of life point of view..' (204-206)*
- '..and manage the risk as best we can..' (208)*

The need for regular review of the swallow for change was also explored by several participants with P1 perhaps providing the most illuminating view (P1, FG, M1, M3, M4, M5, M6).

- P1 *'..we would be there to guide them throughout erm and review them as and as and when required you know it might be that maybe they would want to try eating and drinking whatever they wanted they don't want to adhere to what we're saying but in actual fact if they do end up really struggling chest goes off just feeling utterly horrendous it might be that then maybe we would have a role*

further on I I don't think it's a purely assess and discharge I think it's a a management..' (472-485)

Some participants described this patient group as complex for a variety of reasons including the, unpredictability of presentation and symptoms.

M2 *'..they are complex because they have difficulties at more than one stage of their swallow..' (90-93)*

'..they suffer from a variety of things and as I say they can be quite complex..' (105-106)

The tendency towards this group of patients being a younger age also came up in some interviews with comments related to their increased mobility and intact cognitive state particularly in relation to their capacity to vocalise their views and contribute /influence decision making around risk. This issue is also explored in the theme 'Under your skin' in relation to the emotional impact on the SLT.

P2 *'..younger and more active ..more physically active/cognitively able to follow advice that would let them get away with more risky oral intake ..' (770-775)*

The focus group was in agreement that the HNC patient group represented a complex, variable and changing picture and that intervention had to be tailored to individual needs. This would clearly be the case for any caseload but there would seem to be a suggestion that this is more marked and that change including unexpected change is to be expected more frequently with this caseload. This may be partly due to the complex nature of cases but also to the clinical interventions around its management such as the need for further surgery or the impact of radiotherapy on recovery and symptom management.

All participants described this patient group as complex for a variety of reasons including the number of concomitant issues, the stage of presentation and the rapid changes which can be encountered. Several participants commented on the younger age and intact cognitive state of patients particularly in relation to their capacity to

vocalise their views and contribute /influence decision making around risk. A number of participants commented on the patient's ability to communicate their views, not in relation to capacity but with regard to physical ability to get the message across effectively. Whilst this is not the focus of this study it should be recognised that this aspect arose frequently across the data corpus and may require further consideration in a future study.

Patient/carer led decision making

Many participants referred to situations where the assessment indicated some level of risk in continuing oral intake (in terms of an increased risk of swallowed material entering the airway and potentially causing obstruction or aspiration pneumonia).

Swallowing safety was viewed by some as not taking precedence to the same degree as with other client groups (P1, P2.) Some participants attempted to clarify this e.g. P1 described *'more risky and proactive decision making'*. It is perhaps worth noting that P1 was the least experienced participant. It is interesting to consider whether this perception is more marked for those coming to the area from other clinical fields.

P1 *'..so it's almost a different style of management and slightly more er .. I'm trying to think of a good word to describe it erm not gung ho but you kind of you know you make the decision with the patient and the MDT team [referring to multi-disciplinary team] and everybody you know the patients have a large role to do with it erm '* (148-156)

Several participants commented on the need to be realistic and to focus on maintenance of quality of life. This would clearly not be exclusive to this client group but is perhaps a more visible aspect of this caseload due to the complexity of issues being managed.

M4 *'..but where our our overall emphasis is to try and er maintain or improve their quality of life if they wish to continue eating and drinking, as safely as possible..'* (198-200)

M6 *'..our role I think is to make sure that they're doing that as safely as is possible but also to make sure that we maximise the quality of life.'* (290-292)

Whilst other client groups clearly also manage people with a deteriorating swallow (e.g. progressive neurological diseases), this group are reported to demonstrate not only deterioration but also an irregular pattern of symptoms. Problems arise at various times and cannot easily be predicted requiring longer term involvement of the SLT in order to intervene and modify advice.

Some participants described challenges around rapid deterioration in the patient's condition nearer the end of life, resulting in disbelief and shock for the patient, family and team. In these situations, participants reported changing their previous recommendations with some difficulty reported in conversations about changed advice in terms of a concern about being seen to 'go back' on what had previously been in place and the risk of demoralising the patient

P2 *'..you're talking about and eating and drinking but they've been told before it's not safe so there's a lot of things that you almost sound like you're contradicting things in the past and you have to do it very carefully so that they still trust the team and don't think you're..flip-flopping ..' (367-374).*

M3 *'...now they're at this slightly different phase of their treatment where actually a lot of those don't do that's are now..that's ok to do that if you want to do that that's absolutely fine...' (288-292)*

M6 elaborated on this point by describing a view that the problems are different and arise in a different pattern to other client groups resulting in a bigger window of intervention for the SLT and some difficulty in predicting future needs. M6 also described a perception that SLTs working with this client group have to continue to monitor patients rather than gradually 'backing off' as the patient improves as with other client groups.

M6 *'..so I think the window of intervention for dysphagia in head and neck cancer can be much bigger and the amount of intervention and type of intervention we have to give is in a different pattern if you like..' (229-232)*

'..we maybe need to not just monitor these patients longer term but be prepared to intervene at stages where perhaps other Speech Therapists with other client groups are beginning to back off sometimes that's when we're becoming most active in the patient pathway..' (180-184)

M4 discussed managing the social and psychological impact of being unable to take normal diet and fluids at this stage of care.

M4 *'..and when someone is approaching the end of their life erm you know it's it's one thing that you think really you should be able to do is.. have a cup of tea or chat.. do the things that that you were able to do before.. to some extent..'* (281-286)

'..and the whole kind of culture around eating and drinking is really important to us..' (286-289)

In general, the participants demonstrated a high level of awareness of the impact of decision making on patients' lives and there were several comments regarding the level of emotional impact an inability to eat and drink can have on people.

This appears to indicate that the SLTs had a strong sense of how their clinical judgments might impact on the lives of their patients thus further reinforcing the sense of responsibility in choosing to make high risk, patient led decisions near the end of life when in other situations they would perhaps not have done so

M1 and the focus group chose to explore the topic of when patients are totally unable to swallow and how this presents a significant difficulty should the patient still wish to try oral intake. They shared anecdotes of sensitive discussions with patients where these issues had been challenging such as a case where a tumour had occluded the oral cavity. Such examples would be rare in other caseloads.

M1 *'.. it grew at such a rate...ended up occluding her airway so she had a tracheostomy so she couldn't speak she couldn't voice she couldn't swallow there was nothing there was no way past this tumour but we played a major role...'* (515-527)

FGB *'..it was consistency of foods for him and it was very very small amounts because the actual space for him to swallow through was was s was so so limited by that time..'* (436-439)

A in the Focus Group commented that it was often easier to manage when someone was totally unable to swallow and the situation was clear cut rather than 'grey areas' which left the SLT with a complex risk management decision to make.

FGA *'...in many ways it does make it ...I hate to say easier...if it's just physically impossible ..'(489-492)*

'..when there's the grey area and there's a little window..' (494)

Cases where the patient chose not to adhere to SLT advice were also reported as problematic particularly if there was some query about whether the patient was fully aware of the potential impact of that choice. Several participants commented on how they went to great lengths to fully discuss options with patients and others and expressed a need to ensure that they had not only empowered the patient to make their own choice but had also adequately informed them about the potential impact of that choice.

FGC *'...I was quite worried about it at the time...what did he understand..was he taking on the risks .. did he fully understand...we went over it and over it and discussed it fully...it was alcohol for him..' (542-547)*

These situations seem to be a cause of concern to participants who reported a need to discuss and ensure that they had fully communicated and documented the risks to the patient, carer and multi-disciplinary team. Difficult judgments around how to finely balance the needs and expectations of the patient, healthcare professionals and carers/family was also a prominent issue in many interviews which seems to represent a significant part of the SLTs focus. It would appear that perhaps in such situations the SLT had awareness of the potential for litigation and therefore sought to ensure that they had fully communicated and documented the risks to all concerned. These issues were reported as more complicated in cases where patient capacity was unclear as decision making could not sit with the patient and required broader consideration. This is further discussed in the theme 'Under your skin' as it appeared to represent a significant burden for the participants.

- FGA *'...I think we're so aware of our documentation erm covering our decision making especially when you're just getting...that experience and you are aware of all these risks...making that judgement..'* (587-593)
- FGA *'...they are having to be aware of that ethical decision making process and the responsibility for that the legalities of it which are quite essential with that patient group..'* (1152-1158)
- M6 *'...I do think, that we are in an increasingly litigious society ...where patients may or may not want to sue but professionals I think worry more than they did ten years ago about if I do the wrong thing here I could get sued..'* (1374-1379)

Shared caseload management came up in the Focus Group and led to a discussion around less experienced SLTs or those without an established relationship with the patient perhaps taking a more clear cut decision around risk and opting for recommending that the oral route was unsafe whereas the existing SLT may well have retained oral intake within the risk management focus. The group talked about how they would manage this and suggested sitting down with a colleague and exploring the patient perspective in more detail with the aim of identifying any potential alternative options to a nil oral recommendation.

- FGA *'...if you ..have a shared caseload and the other therapist involved is maybe not seeing as many of these patients and they maybe put them NBM..'* (nil by mouth) *'...managing that as well...'* (857-864)
- '..let's sit down and have a chat and see is there a way to allow the patient to have some oral intake the safest way ...so it's important..'* (866-872)

A number of participants raised the issue of patients choosing not to continue oral intake for a variety of reasons such as discomfort, awareness of the impact of aspiration or of a potential choking episode on themselves or on carers. In some cases alternative nutrition alone was reported as being acceptable to the patient as eating and drinking had become a lesser priority or too effortful for them to consider. In these cases, some participants stressed the need for patients to be given sufficient information and control of their own care to enable them to communicate a choice not

to eat and drink. Some commented on an assumption by healthcare professionals that most people wish to eat and drink at the end of life which they felt was not necessarily accurate (M1).

P2 *'..I think the assumption always has been people want to eat and drink if they're at that stage they don't mind what it does to their chest so they don't need information from the SLT about what will lessen the effect on their chest 'cause they don't care about it anymore its academic..' (997-1003)*

M1 *'..who makes the decisions I think if patients aren't able to make their decisions themselves for if they want to eat and drink who makes that decision?' (1146-1151)*

'..we have a lot of documentation about the DNR er do not resuscitate it's a medical decision nothing to do with the patient or the next of kin it's a medical decision..' (1151-1157)

Participant P1 and FGA also discussed the need for SLTs to be comfortable in their knowledge of anatomy and clinical knowledge. It seems that they considered this knowledge to be an essential element with this client group which may be a reflection of the complexity and variability previously described.

P1 *'..because you know you're piecing together this huge puzzle and it's you know you have you have to be I think very comfortable in your knowledge of anatomy and what's supposed to happen when and what the effects of all this treatment can be and you know kind of like bring it all together so I sup I suppose that's what I maybe I mean is it's a bit more pro-active you know that your you're doing things to try and maintain what people have..' (197-210)*

FGA *'..I think we need to have a background in head and neck to have an understanding of the changes in anatomy and physiology and treatment ..effects..' (1123-1127)*

Some participants made reference to dysphagia with the HNC group being similar or a continuation of other areas of clinical work with transferrable skills (M3, M5).

M3 *'..I think it's rewarding ..I think it's a rewarding part of the job.. and it's a natural continuation ...it's not totally..it's not a separate box it's a natural continuation of everything else that we do I think ..'* (1336-1341)

M5 *'..I had worked with non head and neck patients who were at that stage and so I think that experience was you could to transfer in some ways..'* (478-482)

Participant M6, whilst taking the view that dysphagia was different with this caseload, suggested that there were similarities in terms of how the dysphagia was described ('oral or pharyngeal stage') but went on to discuss how SLTs had to consider other wider issues with this caseload which were very specific to it e.g. in relation to post surgical function.

M6 *'..in some ways similar to other client groups so that you could sub-divide them into oral stage problems, pharyngeal stage problems we also have to think about the issues with dysphagia around feeling post surgery..' (i.e. changed sensation). '.. issues with erm other treatments that can cause dysphagia so it's not always just surgery..' (148-155)*

There was some evidence of inconsistency within some interviews, M1 initially appeared to suggest that dysphagia management at end of life was different but later apparently contradicted this statement in stating:

M1 *'..so..quite often we're involved in managing their swallowing problems at the end of life and that can take a different role.'*(142-144)

'..I wouldn't say it's a huge difference from how I manage any other dysphagia...'
(re end of life dysphagia role) (405-406)

The positive experience of being able to make a difference by introducing swallowing strategies was also raised. Common strategies reported by participants for managing risk and maintaining swallow function included employing swallowing exercises, maneuvers or strategies or modifying the texture or nature of oral intake (e.g. temperature). Quantity and timing of oral intake was also a consideration in this respect. One participant chose to comment on the impact of a lack of variety of modified diet across the week on hospital menus:

M3 *'.. moving from their rehabilitation of swallowing active rehabilitation..sometimes using ...dysphagia exercises..'* (136-139)

M4 *'..trialling different textures which I would think they might be able to try..safely depending on what they've told me and what I've seen when I've had a look around their mouth...'* (412-419)

'..a lot of these patients because they're cognitively quite intact you can often try strategies ...head turns or chin tucks ..' (referring to postural movements used to reduce risk of foods/drinks entering airway) (432-434)

'..other positioning which you think is going to be helpful..' (437)

M2 and M5 referred to patients often already having alternative means of nutrition and hydration in place where the focus then became maintaining comfort and quality of life by enabling people to continue oral intake whilst attempting to minimise the risk.

M5 *'..very often they've been given some other means of nutrition before they get to that stage.. and their oral intake is really just for comfort... I find that more difficult.. in my view that unnecessarily prolongs a stage of the patients life that I don't think the patient always recognises that before they agree to the PEG..'* (Percutaneous endoscopic gastrostomy) (241-251)

Some participants described challenges around rapid deterioration in the patient's condition nearer the end of life, resulting in disbelief and shock for the patient, family and team. In these situations, participants reported changing their previous recommendations with some difficulty reported in conversations about changed advice as discussed earlier.

Pain control and awareness of sensitivities was introduced as another clinical management issue and the impact this had on SLT intervention ranging from being unable to advise until pain was adequately managed (M5) to the SLT making sure they were considering the impact of the type of foodstuffs given on someone experiencing pain in the oral cavity (M2).

M2 *‘..being aware of the taste because they have reduced sense of taste/smell and that’s a big issue which can be that they don’t want to have anything..’ (142-145)*

‘..or if something’s salty or spicy or sharp its gonna cause them pain so you have to be very aware of that..’ (147-150)

‘..you also have to be aware that if they have a dry mouth they’re not going to be able to taste anything anyway..’ (150-152)

‘..and if they’ve got mouth ulcers or sores then they could just be in pain..’ (155-157)

M5 *‘..often it’s pain is more the issue which we can’t do anything about apart from advise about what might be easiest..’ (104-107)*

‘..but really the issue of pain control needs to be dealt with elsewhere before they can really get best benefit from our department..’ (108-110)

Another issue related to patients with an additional communication impairment which inhibited them from readily voicing their views or contributing to decision making. Some participants commented on the patient’s ability to communicate their views in relation to physical ability to get the message across effectively (M1 M2, M3, M5, M6). Others commented on the difficulties arising from caring for adults with incapacity (FGC, M4). Whilst this is not the focus of this study it should be recognised that this aspect arose frequently across the data corpus and may require further consideration in a future study.

Managing expectations (P2, FG, M3) and ‘giving permission’ (FG, M3, M6), to take risky decisions was also a common topic which appeared to represent a significant challenge for the SLTs in terms of both their clinical management and their own perception of their role.

M3 *‘...some of them will need to be given permission to go with what feels right rather than what they think the doctor’s going to say..’ (294-296)*

M6 *‘..I think sometimes there is a very good case for perhaps allowing the patient to have some oral intake even though it’s not safe because of the impact erm that not being able to eat and drink can have at that stage in life..’ (267-272)*

'.. I think we might have a role in giving permission..' (1147-1148)

This coupled with supporting patients experiencing what M6 described as a '*dawning realisation that this is it..*' (568-569) presented complex, highly sensitive and time consuming management situations for participants

It would appear that the participants had clear views about what issues were prominent within clinical management, risks and skills and how this impacted on their approach to patient led decision making. There is clear awareness of the implications of high risk decisions and the wider context in which they sit.

FGA *'..if they are swallowing they're aspirating to the extent that they're unwell.'* (258-260)

'..it's tipped them over into that high risk, unsafe category..' (262-264)

'..and that leads into difficult ground..' (266)

The data suggests that participants viewed this client group as highly complex and sensitive in nature requiring careful management ideally from clinicians with an existing relationship with the patient and carers.

'Under your skin'

This super-ordinate theme encapsulates the participants' experiences of what it felt like to work in this field and how they experienced support from peers, MDT and others. This topic was not directly included in the interview prompts and arose from providing the opportunity to discuss experiences.

There were many striking comments regarding this topic, one of the most pertinent came from M6 who stated that these issues get '*under your skin*'. This seemed to be a clear description of what others were reporting and was therefore selected as the title for this super-ordinate theme. The selection of this as a theme title also ensured that it

arose directly from participants rather than the researcher selecting a name for the theme, which may have inadvertently resulted in some degree of researcher interpretation rather than representation.

M6 *'..erm and I think we do just learn to cope with it I think you have to because otherwise you would be quite suicidal but I do think it's fair to say that just every once in a while there's once that gets under your skin a wee bit..'* (626-632)

What it feels like

This section discusses the wide range of reported emotional impact on participants and includes the following topics: can't fix/perception of role, worse when young cognitively able and vocal, length of relationship, fear of litigation, dealing with dying/coping, whether to be involved/how much to say, guilt/preying on your mind, impact of setting, frightened to go into it and over-ridden

Several participants discussed their experiences of situations where the SLT was unable to provide any solution to a patient's difficulties (P1, P2, FGC, FGA, M1, M4 and M6). P1 in particular, seemed to demonstrate clear discomfort with the idea of not being able to achieve improvement in these cases and frequently made reference to *'fixing'* the problem. A sense of failure is also suggested in P1 describing:

P1 *'..it's really like you are the last person to pile on top of this pile of negativity..'* (277-279).

P1 *'..cause I think a lot of the time our role isn't that well understood generally and I think sometimes it can be portrayed that we can maybe fix things..'* (557-563)

Whilst, the focus group and M4 appeared more reconciled with the idea that nothing could be done, they also reported a sense of *'feeling a bit helpless'* and M4 expressed a desire to offer a solution.

FGA *'..It's the real shock of that (nothing more can be done) 'cause that can absorb the full team if it's an unexpected recurrence and a rapid decline and er it's just a shock..'* (1307-1310)

FGC *'...much the same I think sometimes...you feel a bit helpless..that there's nothing you can do these things are outwith our control and erm its sad patients that you like and you work with and you care about..'* (1334-1338)

M4 *'..but for somebody where there's a fistula or where the tumour is so extensive..even getting things into the mouth let alone enabling them to swallow...there's really nothing we can do...'* (312-317)

M6, as perhaps the one of the most experienced participants, appeared to accept the situation of being unable to add anything further in stating:

M6 *'..and erm that's hard to realise that actually we did everything we could and the patient did really well but this horrible disease has come back and there's, nothing we can do about it...'* (646-653)

The Focus Group, M2, M4 and M6 all discussed the impact of end of life on themselves as well as on the patient, carers and the whole team. The focus group discussed *'managing the disappointment'* of a deterioration, and patient distress. FGC commented on it being *'bad news all the time'*.

FGC *'...and sometimes it feels in this job its bad news all the time and it can be quite difficult sometimes..'* (1294-1297)

M4 echoed this, in describing a feeling of being *'useless'* in situations where there were no further options.

M4 (re unable to help) *'..and then you actually feel pretty useless to be honest..'* (318)

M2 provided an illuminating view of how these pressures affected this participant, with an emotional account of the impact of a perceived accumulation of negative events. This participant later went on to describe how support is accessed.

- M2 *'..but what I find with me is this is just a personal thing I think that I don't get upset or distressed...by the patients departing erm but every so often I can go for months and maybe a year on end and then all of a sudden the raw emotion just spills over.. (388-394)*
- '.. and it's usually a patient that...I haven't been particularly heavily involved with but it's as if it's an accumulation (394-399)*

Three participants commented on how care of the younger patient had an influence on them (P1, M2, M6).

- P1 *'..mm... difficult issues I suppose it's the the emotional aspect of how things affect patients especially you know if they're if they're very young patients we have patients at the moment who are very young..' (495-500)*
- M2 *'...probably erm some of the, younger age patients..' (re memorable cases) (332)*
- M6 (re students) *'..Mostly when there's a young patient involved... as a young person themselves they won't want to .. see somebody else who's maybe not that much older than they are erm going through this awful disease..' 622-627)*
- M6 *'..or I think the the ones that often I find affect me most are where it is somebody who's a little bit younger than I am..' (637-639)*

M6 was the only participant who attempted to suggest why this might be the case, whilst the remainder mentioned the issue but did not attempt to elaborate on the reason for it.

The cognitive ability and vocal nature of patients in this caseload, was also raised as an issue. Participant P2 considered how this influenced what decisions could be made in the comment:

- P2 *'..I think perhaps the head and neck caseload is of a often a group of patients who are very vocal about their feelings about their care and they cert they don't maybe have cognitive difficulties as often often although they sometimes do as some other patient groups*
- '..erm they can be younger and more active in other ways or they are more physically able and often cognitively able to follow advice that would..'*
- '..let them get away with more risky oral intake..' (762-775)*

The impact of knowing the patient very well, over sometimes what appeared to be a significant period of years, was raised by three participants.

P1 *'...it's actually really sad, it was a really lovely patient and everyone was so sad when he passed away just because I think he'd been.. patients who I think have you know head and neck diagnosis can be around for years..'* (356-363)

M1 *'...I felt quite confident...I knew the patient very well because we'd had this long patient journey with him...'* (284-286)

M2 *'..for me..seeing somebody who you have seen relatively well ..being really unwell..'* (521-524)

'..but that was actually a very positive experience for me that we'd had this great long time where he'd come and gone for various episodes of care and we'd got through quite a number of crises..and the patient knew his limitations and he knew when he was diagnosed with the recurrence..' (792-801)

The focus group discussed how, in cases where an established relationship had developed between the SLT and the patient in advance of the immediate situation, this influenced clinical management. Participants reported that this resulted in increased patient confidence to try SLT advice. There were also comments from M3 suggesting that a long patient relationship, enabled the SLT to broach more sensitive conversations about prognosis more readily.

FGB *'...his confidence to try was better because of the relationship we all had...and the family supported me with the position..'* (439-441)

M3 *'..SLT is qu is reasonably well placed to do some of that stuff (discussion of choice) especially around DG in fact we're..one of the best placed people to do it 'cause we understand DG, we understand swallowing issues we will often already have a ...long standing relationship with the patient although not always...'*

'erm but we have the time and the skill in terms of communication to open up those discussions..' (342-350)

M6 whilst describing the field as *'really, really rewarding'* went on to discuss the relationships built up between the SLT and the patient and a need for the SLT to *'give*

something of themselves..'. M6 discussed the need to learn to cope with such difficult situations as unexpected cancer recurrence, *'otherwise you would be quite suicidal'* (626-632) which is a very powerful statement.

M6 *'I think it's really, it's really really rewarding I think erm...it can be quite upsetting because although you...aim to be and are always very professional we do form a relationship with patients.'* (588-591)

'.. because, the patient doesn't get the best from you and you don't help the patient to the best advantage in these situations when patients are very emotionally fragile if you don't give something of yourself, you can't be, I don't think you can be stiff brush up the back and very detached that's not what these patients need..' (591-598)

'.. erm and I think we do just learn to cope with it I think you have to because otherwise you would be quite suicidal but I do think it's fair to say that just every once in a while there's one that gets under your skin a wee bit..' (626-632)

M6 raised the issue of potential litigation and in this regard, suggested that SLTs worried about making a wrong decision and being sued.

M6 *'..I do think, that we are in an increasingly litigious society ...where patients may or may not want to sue but professionals I think worry more than they did ten years ago about if I do the wrong thing here I could get sued..'* (1374-1379)

Whilst there was a sense that most participants had a concern about this, it was not explicitly stated in most cases.

FGA *'..I think we're so aware of our documentation erm covering our decision making especially when you're just getting...that experience and you are aware of all these risks...making that judgement..'* (587-593)

FGA *'.. ...they are having to be aware of that ethical decision making process and the responsibility for that the legalities of it which are quite essential with that patient group..'* (1152-1158)

P1, M2, and M6 specifically discussed the issue of the speed of presentation and rapid decline, which can be encountered with the HNC client group. Both P1 and M2 recounted anecdotes of how this had affected them and the team. M2 gave a poignant account of a case which was reported as *'quite traumatic'* but which was ultimately regarded as positive, having had the rare opportunity to say goodbye to a patient.

P1 *'..that has really affected people because of the presentation and how quick it was and the age of the patient and and the you know the kind of the real physical changes in this in this patient erm so I think it can be quite difficult..'* (495-528)

M2 *'..I was asked to go and assess his swallowing which I did but found that quite traumatic initially...went into professional mode or went into professional hyper drive not to show the patient how concerned I was that he had deteriorated...'* (356-362)

'..that was a very positive closure..quite often you don't get a positive closure you know the patient is not going to survive but you don't get the ability to say cheerio it's going to be alright and yes we've done this and..it's had its challenges ..and I know it's been difficult for you.. but it was good just to say goodbye..' (821-834)

M6 too, described these situations as *'quite upsetting'* and suggested a need to learn to cope with such events.

M6 (re forming a relationship) *'..but as a net result of that it can be quite hard to watch them going downhill and to see them passing away sometimes with you know clear distress and well you would hope not in pain... so it it can be quite upsetting..'* (598-606)

'..I do think having worked in the field for as long as I have you do.. I don't know if I want to use the word detached 'cause you're not detached you learn to cope with it and not go home and bubble into your glass of wine every night of the week..' (606-612)

M4 and M6 expressed some concern about making the decision whether or not to be involved with particular cases at the end of life.

M4 *'..but at the same time you don't want people to feel like ...you're not available to them.. or that you're ignoring them...because if you go into the ward...they're*

very poorly and you're passing the door and you're thinking should I just pop in but often it's just not appropriate..' (482-491)

'..maybe our own sense of discomfort or feeling a bit useless..not really knowing what actually our role is with a particular patient ..' (695-697)

M6 *'..I think sometimes SLTs it's not so much that they don't know what they could do for the patients but whether they should..' (1238-1241)*

'.. I think sometimes we don't understand enough about the process of end of life and what might be happening with that patient and how long it might take and issues around that so we know whether we should or shouldn't offer some intervention of some sort or advice or whatever so again that that kind of goes back to the knowledge and training..' (1245-1255)

Some were concerned about how to approach conversations focussed around how much they should say to the person and how much the person was already aware of their situation, as well as a lack of clarity about the patient's level of acceptance.

FGC *'..You're anticipating significant dysphagic problems the patients aren't at a stage to take that on board...' (191-192)*

P2 *'..I personally find it quite difficult seeing people at the end ..' (434-435)*

'..I'm not quite sure exactly why it is..' (437-438)

'...another..' (difficult aspect) '..is how much the person already understands of their situation..' (458-459)

'..I think I've always got that massive fear...about spilling the beans...about something that somebody didn't already understand..' (629-631)

'..just knowing where you stand in terms of how clear you can be in your language at any one moment about what the situation is..' (re Q about most challenging aspect of end of life dysphagia) (697-701)

'...I think some personalities cope better with that sort of patient group but I am not sure I'm one of those so ...I think perhaps that's one challenge..' (1127-1130)

There were also concerns about intruding or offering input when it was not appropriate.

M3 *'...there's a ..kind of incredibly ..strong desire not to intrude on somebody's privacy...not to appear to be talking about something which is now irrelevant to*

them..patients/families ..moved on much further than you think they have in terms of ..acceptance..' (743-751)

M3 talked about visiting a hospice for the first time and what strategies had been employed to enable M3 to manage this new experience.

M3 *'..I think the first thing was realising that here are patients who are not going to get better..that was a hospice and so those patients erm were er in a sense actively dying ...' (912-916)*

'..I think I felt nervous and I felt er ..like I had the potential to be ineffectual at any moment..' (925-926)

Members of the focus group and participant M5, discussed the issue of guilt and how patients preyed on their minds.

FGB *'...even the length of time that we've all been working with this I think the guilt aspect of denying foods and fluids to somebody is still with me..' (479-482)*

FGC *'..I suppose quite anxious about him you know he preyed on your mind a lot because you knew it was very risky..' (554-557)*

M5 *'...the quandary of knowing whether what you're suggesting is right the best for the patient..' (427-430)*

This seems to resonate with previous comments regarding the lack of clarity of the SLT role and the uncertainty about what is acceptable practice discussed earlier.

P2, M1 and M3 all discussed the setting in which end of life care is managed and described its impact on them. P2 in particular described the difficulties of discussing sensitive topics in an open ward, where other patients nearby would be able to hear the discussion. P2 appeared to find this particularly difficult and commented that these people should be in side rooms rather than the open ward environment.

P2 *'...partly sometimes..people should be in side rooms and they're not...'* (438-440)

'..you're aware of talking about very upsetting things in a 4 bedded room that other people can hear ..' (442-444)

'and so you find yourself getting in a fankle how to phrase things... helpful to others ...but not confusing..' (to patient) (451-454)

M1 and M3 both discussed a perceived difficulty in people accessing appropriate care at end of life, with a sense that different patients had different experiences of being in an acute ward, some gaining a sense of security in this setting and others perhaps being seen as 'stuck' in an inappropriate environment. This appeared to be a clear source of distress for both participants.

M1 *'..I think I get quite upset seeing patients getting stuck in the hospital ..'* (809-810)

(re patients in hospital instead of hospice) *'..oh it upsets me quite a lot..'* (886)

M3 *'..I find it quite difficult ...to get our patients into hospices for a whole variety of reasons..'* (573-574) (did not elaborate)

'...a lot of patients want to go home...there are also quite a lot of patients who are very safe on our wards and want to stay here they know..the nurses really quite well..they feel safe they feel cared for..' (576-580)

M6 suggested that care in the hospice setting worked more effectively in terms of multi-disciplinary team working.

M6 (re hospice) *'..things are very different from the acute environment I do think that it's better for the patients but it's also a better multi-disciplinary working environment ..'* (491-494)

P1, the Focus Group and M6 discussed their perceptions of how they themselves as well as other SLTs and students, viewed the idea of entering the field of both HNC and end of life. Language such as '*frightened*' '*hate to do it*' '*scary*' and '*terrified*' was used.

- P1 *'...a lot of people are very very frightened of doing it and would hate to do it...' [stresses the word hate] '..and you kind of you you hear that from people..' (re SLTs) (1006-1010)*
- FGB *'...We need to stop making it a scary field to be going into..' (1187-1188)*
- FGC *'...making sure people are aware how complex they are...I do think there are barriers put up and people are scared to go onto the ward...it's important that it isn't made complicated..' (1230-1236).*
- M6 *'...the students I find either embrace this sphere of work or they are terrified absolutely terrified, and over the years I've had quite a few students who have said, please don't take this the wrong way but I'm so glad that the placement is over I couldn't do this job how do you cope with that?..' (617-622)*

A common topic amongst most of the participants was the relationship with medical and in particular consultant colleagues. Whilst there were positive accounts, by far the most prevalent accounts reflected some perceived problems with working relationships. P2 appeared to have experienced considerable issues in this respect and volunteered a view of its impact:.

- P2 *'...yeah the idea seems to be that SLTs would like everyone to be nil by mouth or you know we are super over cautious rather than pragmatic in the way we make our decisions..'*
- '...I think that's how I'd put it..'*
- '...oh it makes me feel desperately frustrated..' (241-250)*

The Focus group too, touched on this topic, which at times appeared to be difficult for them to discuss (participants tended to use quieter voices and appear more hesitant). FGA suggested that being over-ridden by consultant colleagues made A want to withdraw from the care.

- FGA *'...on that rare occasion...if a decision was over-ridden which is very rare but it's happened in the past and that's difficult for the patient as well as the SLT..' (796-800)*
- '...you immediately want to withdraw...from the care..' (re being over-ridden) (802)*

'..patients have been referred back please come back well this is what the outcome was and why if you want me involved this is what we can do ..'(804-808)

M1, M5 and M6 also related accounts of having been over-ridden by consultant and MDT colleagues. There is a palpable sense of frustration across all of these comments, particularly those of P2, which seemed to be a source of concern for the participants.

M4 whilst having previously described good relationships in the participants own workplace, chose to comment on the importance of having good relationships with consultant colleagues. It is unclear why M4 would choose to do this without experience of this issue but perhaps it is a perception based on previous experience or on anecdotal reports from colleagues.

M1 *'..quite often they take the decision oh we'll just let the patient eat and drink that seems to be the thing that erm I'm a bit annoyed about because it's not their decision it's the patients decision they might not want to eat and drink ..' (459-463)*

M1 *'..maybe just feeling a little bit under-valued as to what our role is..' (503-505)*

M4 *'..probably the biggest problem is..probably the consultants because if you've got a good consultant who values your input..the communication is going to be much better than ..a consultant who doesn't or maybe has more pressing matters..' (929-936)*

M5 (re consultant giving swallowing advice) *'...if you're being asked your opinion and your professional opinion and people don't appear to er I think it undermines us a little bit I don't think it necessarily is the best thing for the patient..' (195-198)*

M6 *'.. it's very much seen as a hierarchical structure with everybody in their place in the pecking order and the lower down the pecking order you are which sometimes is a position allocated to you because of poor understanding of what you have to offer then the less you have to be paid attention to erm and I think that ripples right down..' (441-452)*

(re probe which staff are hierarchical?) *'..Oh the consultants very much.. it's very much an attitude of well I hear you but I don't have to listen to you because, I have seniority and I know best and.. that's sometimes, alright for the patient and sometimes it's not..' (456-464)*

Support

The issue of support was not included in the interview prompts but was introduced by early participants and seemed to be of importance to them. It was therefore included in subsequent interviews.

- FGC *'..It's exhausting you know if you're getting to a stage...of if there's nobody to talk to with it it would be absolutely dreadful I mean with a support group even with us meeting..' (referring to MCN SLT sub group) (1315-1318)*
- FGA *'..if I didn't have a job share and I was just one person within that I would not be able to do the job you do need to discuss..' (1324-1326)*
- M3 *'..I get a lot of support from my immediate colleagues so I get massive support from [identifiable name of SLT] because ..she's the person I work with and any..colleague that I am working with..I lean on them for support..' (1284-1296)*
- M4 (re anything you want to add) *'..again its peer support..I think that's probably the biggest thing..and it can be..being able to talk it through with somebody who can give you ..a different perspective or..confirm your own perspective on things..' (1014-1019)*

Most participants expressed a clear need to share and discuss challenging cases with colleagues, either directly or indirectly (such as via telephone conversations). This was achieved through shared working arrangements such as sharing patient management, job sharing or overlapping with part time colleagues. This type of support seemed to be viewed as a positive arrangement, which enabled direct discussion and exchange of information.

Local clinical supervision sessions were also viewed by some, as being an effective source of direct support as outlined by M2:

- M2 *'..if you don't have..the resources working with a MDT specifically for HNC and ENT then supervision definitely you need to have somewhere to be able to deal with the emotion of all this because unless you're inhuman its gonna get you at some point..' (984-989)*

Access to experienced, senior support and the support of MDT colleagues also appeared important to the participants, particularly those who were newer to the field.

More experienced participants tended to discuss wider access to support which included indirect measures such as via clinical networks, the professional body or professional advisors. This is included in the theme 'Trained and equipped – what is needed?'

FGC *'..I think as a professional you need a team support for dealing with these patients 'cause it can be very stressful and erm you know upsetting..'* (1290-1292)

M3 *'..I think the multidisciplinary support is really really really important..the support of my SLT colleagues of course is really important..I really enjoy team meetings...'cause I think that's a great opportunity ...I've been able to discuss a difficult sort of case...I found that really useful..'* (1306-1317)

M4 *'..if there was something troubling you that you felt you couldn't quite manage/needed some advice on I would discuss it with one of the other people who work in the same field or even somebody out of the field it doesn't have to be but..people in the field just have a bit more of a feel for the kind of difficulties..'* (578-588)

M6 *'.. I think w we're fortunate in that we have our managed clinical network SLT sub-group there's a very small core of us in our geographical area, I think we communicate really really well we exchange ideas.. there's a new book have you seen it er oh here's an article I've read, oh I've got this patient I'd like to speak about..'* (1502-1510)

‘Communication isn’t always wonderful’

This super-ordinate theme represents the numerous comments regarding communication issues related to everything from communication with the patient, family and fellow SLTs, to communications with the wider team. It incorporates the main category of MDT working including both positive (part of the team, shared decision making, opportunity for learning) and more challenging aspects expressed by the participants (poor awareness of role, changed recommendations, hierarchical culture, difficulty accessing colleagues and communication) .

The theme was given its title from participant P2, as this comment was felt to succinctly express the views reported.

‘..I do think...communication isn’t always wonderful between junior staff (re medical staff) senior staff, nursing staff and the patient..’ (469-473)

Whilst there were many positive comments about communication, there were also several comments across the data set about communication presenting something of a barrier to SLTs. P1 commented on the positive role of SLTs and on their role in working with all staff. P1 felt that SLTs in HNC care tended to be known on wards and were known by other ward staff as *‘really part of the team’* (319) with more of a role within the MDT.

P1 *‘..where it's I think I think it's slightly different because.. for example here you're on two or three of the same wards all the time everybody knows who are you really are part of the team..’ (315-319)*

P2 reported liking working in HNC, due to the multi-disciplinary nature of the role. M3 reported frequent shared working and liaison with other AHPs, particularly dietetic colleagues.

P2 *‘..I quite like the multi-disciplinary approach..’ (136-137)*

M3 *‘..I think there’s quite a lot of dovetailing with...dietetics in particular we do a lot of joint assessments/reviews ..on the wards and definitely in the combined clinic quite a lot of liaison with dietetics..’ (169-176)*

'..I think working with the dietitian/OT/registrars/consultants too obviously but..being part of the MDT discussion..' (831-835)

The focus group was very much in agreement about the benefits of working within the MDT in that it provided shared decision making, with everyone in the same conversation reinforcing decisions and providing a forum for taking issues for further discussion. FGB and M4 also mentioned how email facilitated team working, whilst FGA suggested that communication was easier when all MDT staff were in the same building. M4 felt that AHP staff being grouped together in one building, presented a positive opportunity for liaison and information sharing. M2 also made positive comments about the MDT in discussing the benefits of liaison, discussion, close working relationships and support opportunities.

FGB *'..I think that's the importance of still having the multi-disciplinary approach to it though..' (559-560)*

FGA *'..It's shared..' (562)*

P1 commented on learning gained from working within the MDT. M3 also placed emphasis on the amount of learning derived from the MDT working environment.

P1 *'..the more work I do the more I learn about MDT roles..' (301-304)*

M3 *'..we have quite..good MDT discussions on Friday mornings..I've learned so much from the MDT I cannot tell you how much I've learned and hopefully will go on learning..' (837-845)*

M3 expressed a very positive experience of working within the MDT and described weekly discharge planning meetings, discussions about planned management, joint working, understanding others roles and good relationships within the team. M3 placed emphasis on team working and its impact on patient care in stating:

M3 *'..as well as discharge planning ...dysphagia often plays out a reasonably..key role..' (in discharge planning) (132-133)*

‘..so that’s a team thing that gets done on a weekly basis..’ (re discharge planning) (135-136)

‘.. so you have to make sure that ..when you give them information you’re telling them that they don’t need to worry about out bit they don’t need to worry about the healthcare bit we’ve absolutely got that locked down we know how to speak to each other/liaise with each other and that helps them to feel safe and cared for which ...is really important it’s very important..’ (262-269)

M3 reported feeling confident about opening up discussions and seeking opportunities to share with colleagues. M2 and M4 both reported positive relationships with consultant colleagues, who were reported as approachable and supportive.

M2 *‘..the consultants here will he will be involved in that and the nursing staff and the more junior medical staff or ENT staff, everybody who knows the patient usually is there or everybody who knows the patient from where we work is there and we ha we do have a discussion about what the patient’s status is and... what is happening swallowing wise and anything else that might be happening..’ (235-241)*

M3 *‘..sometimes it is to ..lead the opening up of the kind of feeding or communication issues..sometimes it’s to respond to and support..colleagues who think that that issue needs to be addressed..’ (619-622)*

M4 *‘..overall I think we’re lucky most of the consultants we have are pretty approachable and ..pretty aware that...there’s something we can bring..’ (937-939)*

Several participants (M4 and M5 in particular), commented positively on their relationship with clinical nurse specialists (CNS), where they were seen as an initial point of contact and a source of prompt updates and information.

M4 *‘..we’ve got a good relationship with the ..CNS here..and good relationships with the consultants..but the CNSs are just much more easily accessible and ..will follow through on issues..’ (911-916)*

M5 *‘..we have two staff members here who I liaise with often they will have contact with the patients pre treatment, during treatment and follow them up at home and they’re very useful for keeping me up to date with when treatment’s planned, the outcome of that treatment, what the next stage is going to be’ (855-863)*

M6 also provided a positive view of the benefits of MDT working stating:

'..so, it's critical and its critical at all stages it's not just about planning the operation it's about everybody discussing the whole patient and looking at what's best for the whole patient.' (1459-1463
'so yeah I'm a big I'm a huge fan of MDT work' (1495)

P1 reported helping other staff to understand SLT issues when asked for advice and supporting nursing staff, in how to assist patients with swallowing difficulties.

'..you know and and to also help the nursing staff who you know if if they're aiding somebody with their eating and drinking and the patients clearly aspirating and are very uncomfortable [emphasises 'clearly'] it can be very uncomfortable for the nursing staff so offering offering guidance maybe when people may

be aren't as aware of our role as they could be...' (910-920)

The majority of participants discussed issues with poor awareness of the SLT role in end of life. M4 provided perhaps the most succinct statement on this issue:

'..the only barrier would be ..a recognition that maybe we could offer something at end of life and that's again down to the awareness of the other people involved with the patient..doctors/nurses recognising that maybe there is an issue..a patient who ..wants to eat..might be able to eat..more easily/safely if we were involved with them..' (631-640)

M6 suggested that a poor awareness of the SLT role impacted on patient management but went on to suggest, like M3 previously, that SLTs had a role in changing this:

'..part of the reason they've not been managed well in terms of the dysphagia has been because of a poor understanding within the medical and sometimes the nursing team about what ourselves and the dietitians can offer..' (366-371)

'..I would see that on both sides not just an understanding from other professionals about what we have to offer but for SLTs to maybe think about what they might be able to offer..' (1320-1323)

M1 also discussed a need to communicate the role with the wider team in stating:

M1 *'...the most challenging thing about end stage dysphagia management.. I think..letting other ...healthcare people see what our role could be 'cause we're either not thought about or under-valued..' (599-603)*

The focus group also raised this issue and suggested that patients did not get access to SLT due to a non recognition of the role:

A *'..I think there's a lack of awareness of our role at that stage...because the care's stopping in parts..' (1052-1054)*

A *'..patients don't always get access to us..' (1063)*

B *'..well that'd be a non-recognition of what our role could be..' (1067-1068)*

M4 suggested that this situation might be remedied by education of other staff.

M4 (re people not expected to improve) *'..one of the challenges of that is to erm try to educate people that we're not wanting to put people nil by mouth because they're at risk ..' (202-204)*

Several participants commented on having experienced SLT recommendations being changed by other healthcare staff, in particular medical colleagues. This issue appeared to represent a significant issue for those SLTs and was also included in the previous theme 'under your skin' in relation to the emotional impact on SLTs.

P2 seemed to have experienced frequent challenges particularly in terms of interactions with medical colleagues. P2 felt that medical staff did not take time to understand the SLT approach and would intervene and change advice.

This was discussed as presenting a difficulty to the SLT, in being faced with a situation of either working to the medical colleagues changed advice or challenging it. P2 stated a view that medical staff did not consider SLT advice or made assumptions about its intention, based on a flawed misconception that SLTs were over cautious and tended to suggest that most people should avoid oral intake. P2 dealt with this by seeing patients separately to discuss conflicting advice and trying to enable the patient to

make their own choices. P2 felt that these issues could not always be adequately resolved and discussed *'choosing your battles'* and avoiding *'rocking the boat'*.

P2 *'...medical staff may not fully take the time to understand our approach or may intervene and change ...not necessarily considering what we have said or advised...'* (184-190)

'it is fair to say sometimes the medical staff don't discuss that with you they then say something different to the patient ..' (194-197)

'..If..something will rock the boat then I won't always challenge it ..'(301-304)

M5 also commented on these issues:

'..sometimes the consultants will mm you know if you suggest something for example a particular type of thickened fluids that you feel will keep the patient safest for the longest length of time, the consultant might go in and say normal fluids. .' (185-190)

M5 discussed dealing with this issue by ensuring that written and verbal advice had been provided, to allow the patient to make an informed choice.

M5 *'.....I think if we have given written advice and verbal advice to both medics and the patient at the end of the day it's the patient's decision on which advice they take on board..'* (200-202)

Within the focus group, the issue of being over-ridden by medical staff was broached. FGA went on to discuss cases where this had occurred and the SLT was later asked to return to advise:

A *'...on that rarel occasion...if a decision was over-ridden which is very rare but it's happened in the past and that's difficult for the patient as well as the SLT..'* (796-800)

'...you immediately want to withdraw...from the care..' (re being over-ridden) (802)

M6 also suggested that this was a familiar issue:

'I can think of patients in relatively recent times who have gotten into difficulties.. we've offered a programme that was going to.. make the patient's swallow as safe as possible while maintaining the quality of life aspect but there's been a gung ho just let the patient have whatever they want attitude..' (379-388)

M6 raised the issue of the influence of cultural factors and suggested that the hierarchical culture of the team, influenced these situations, as well older patients being considered to be more inclined to follow medical advice:

M6 (re probe which staff are hierarchical?) *'..Oh the consultants very much.. it's very much an attitude of well I hear you but I don't have to listen to you because, I have seniority and I know best and.. that's sometimes, alright for the patient and sometimes it's not..' (456-464)*

'..I do think a lot of these patients and carers because so many of them are a little bit older what the doctor says goes so if the doctor says just have X Y and Z then the patient goes ahead and does that and I can think of patients who've got into a lot of difficulty, and, come off worse because ..the result was they got very chesty very quickly and were then nil by mouth when in actual fact that needn't have happened..' (390-398)

M5 raised the topic of ward staff awareness of the rationale behind SLT advice, when providing foodstuffs outside of SLT recommendations and the difficulties around that, demonstrating a flexible approach to the issue:

M5 *'.. they're in pain they (i.e. ward staff) don't always recognise that they need to be careful what they're giving them the wrong temperature erm and if somebody is meant to be on a particular consistency and decides they want a cheese sandwich but I think if there's care and they're watching over them that they're not coughing and choking and they're not going to bother their airway then a little bit of what you fancy at that stage in life is not always a bad thing' (340-354)*

M1 suggested that the MDT was not always in agreement about clinical management and that there were difficulties in accessing colleagues, in order to discuss issues.

M1 *'...sometimes...not everyone's in agreement of what should be done' (189-191)*

'...it's not always that we're sitting round a table... talking the same language so it's difficult sometimes to make sure the patient's wishes and needs are being met..' (198-202)

P2 also felt that access to medical colleagues in order to discuss cases was problematic and presented difficulty for the SLT. P2 felt that medical staff wanted to make all the decisions and had a *'firm lock'* on the care plan.

P2 *'..Accessibility is a problem with senior staff ..' (re medics) (215-216)*

'..because the medical staff...want to be the ones ..making all the decisions that way..' (567-569)

'...sometimes it's a frustrating..poor use of time...when nursing staff have referred...but medical staff really want to keep a firm lock..' (571-576)

M4 raised the issue of communication with consultants and specifically access to medical staff, in being unable to attend the necessary ward rounds for five different consultants.

M4 *'..they hold their ward rounds on different days..that can be challenging because you couldn't possibly attend all the different ..ward meetings so that's quite difficult..' (896-904)*

M4 suggested communication with consultants was as a major factor in effective communication between disciplines:

M4 *'..probably the biggest problem is..probably the consultants because if you've got a good consultant who values your input..the communication is going to be much better than ..a consultant who doesn't or maybe has more pressing matters..' (929-936)*

The issue of not receiving referrals was raised by P2 , M1 and M5 and M6, who discussed situations where SLT input was not requested and there was a need to go and ask and a sense of having been forgotten, or as M5 put it *'at the end of the line'*. P2 commented on the perceived assumption that the SLT had nothing to add. P2 was

of the view that the team viewed SLT input as primarily trying to 'save someone from a chest infection' and that there was no need to refer if that was not a prime concern. M1 discussed the need for education in such cases.

M5 (re asked to talk about MDT communication) '*Or lack of it... sometimes it works well but more often than not I don't think it works very well..*' (799-802)

'.. I'm not sure if it's just our site or if it's a more specific erm professional thing but we're often the end of the line not involved...in any decision making, not asked for information before decisions are made.' (802-807)

M6 (barriers) '*I think sometimes erm just access.. might not know the patient's at that stage nobody tells you..*' (1232-1235)

M1 suggested that there were cases when referral would not be appropriate and recognised that in some circumstances, involving the SLT would not be indicated:

M1 '*..it might not be appropriate if there's lots of other healthcare professionals involved in them towards the eol and they don't want to bombard them with new faces ..*' (989-994)

Inappropriate referrals were also raised by P2 in terms of the resultant perceived poor use of time, in seeing people for whom the SLT had little to offer.

P2 '*..sometimes you're referred people for whom you can't add much..*' (564-565)

In relation to communication with the patient, P2 talked about a sense of contradicting previous recommendations, when modifying advice at later stages of care and the need to do this carefully to ensure the patient retained trust in the team.

The issue of the team assuming that people at end of life will all want to eat and drink, also came up with P2 stating that this was not the case but doubting whether this would be considered in the wider team (See 'Not an all or nothing,' pp 126). M5 suggested that in those cases where the patient was more vocal, communication was more prompt and effective.

M5 (re when MDT communication works well) *'..I think that more often happens where the patient's vocal... it makes other people sit up and pay attention and things happen quicker or information gets disseminated more timeously and appropriately but that isn't always the case for that client group..'* (827-836)

The focus group and M2 discussed team communication difficulties arising from hospital patients being housed on wards other than the main head and neck wards, where perhaps ward staff were unaware of current issues or a need to alert the SLT to the admission.

FGA *'..problem can arise if the patient maybe if it's an inpatient and their outwith the head and neck ward and and under another team, things can become quite fragmented, communication can be difficult..'* (610-613)

M2 *'..but they..'* (re in-patient admissions) *'..could be somewhere else and nobody says..'* (i.e. tells SLT) (909)

'Trained and Equipped'

Encapsulates experiences of participants' current posts, preparation, under-graduate and workplace learning, sources of information, service delivery issues and what they felt was needed in the future in terms of guidance, professional profile raising and presence. In addition, participants comments regarding their perception of a changing landscape were included in this theme.

This super-ordinate theme was entitled 'Trained and equipped' which was a concise phrase taken from a focus group participant, during their discussion of the issue, which it was felt would provide a suitable title for this overarching theme:

FGA *'..we need to continue the care for the patient at that stage..'* (1096-1097)

'..in addition to that its whether SLTs are trained and equipped with the exposure to be able to have the confidence to assess and make these difficult decisions..' (1097-1101)

The participants varied in the specific nature of their individual posts with five stating that their remit crossed a number of areas with a broader caseload (P1, M1, M2, M4, M5).

The remaining participants, whilst still reporting a remit for other clinical cases, reported that HNC was a key component of their current role (P2, FGA, FGB, FGC, M3, M6).

Settings, as a result of the nature of the study, were predominantly acute hospitals with some participants reporting some domiciliary and hospice input (FGB, M3). The level of experience of HNC also varied from five months (P1) to twenty four years (M6). Some participants reported having an additional managerial or clinical specialist remit alongside clinical duties (FGB, FGA, M6.)

Most participants reported on the job or experiential learning. Participants discussed the positive impact of in house 'on the job' training, case discussions and having the opportunity to shadow peers.

P2 *'..I would say on the job..' within HNC dysphagia...' (838-839) '..I think it's just on the job and familiarising yourself..' (851-852)*

'...peer support..' (857)

M2 *'....I would say for me lots of it has been experiential but there's nothing out there that's specific to H&N..' (575-577)*

M4 *'..pretty much on my feet I think..' (523)*

Some participants appeared to have been able to access some form of external training, although this seemed to vary considerably in its relevance and content. P1 discussed a recent external course intended for SLTs new to HNC and related how this experience had raised P1s confidence and provided opportunity to ask questions:

'..make me feel confident..' (re training course) (681-683)

'..asking things..' (re training course) (685)

M4 and M5 also described previous attendance at external training. M4 went on to suggest that it had not been specific to SLT requirements:

M4 *'.....many years ago..when I started..I might have attended ..a day course on ..palliative care..not specifically about dysphagia..managing the medical side of things..'* (524-531)

M5 *'....I didn't have any training when I was a student there was no lectures no information nothing we were advised to read and so on..'* (484-488)

'..it was learning on the spot from my manager at the time..'(488-489)

'..there wasn't anything specifically for or by Speech Therapists..' (498)

Several participants reported that they had attended training via a hospice, with the consensus that whilst this did not offer specifics relevant to the SLT role, this type of training was of benefit.

FGB *'...we do in-service training through to the hospice...so we contribute to that and we benefit from it..'* (913-916)

M2 *'..and I was very fortunate in the early years that..we had training from the hospice..there was a big drive for palliative care..'* (417-421)

M6 *'..they used to do erm a quarterly evening training thing.. it tended to cover there were relevant things that came up like pain management..'* (756-760)

M1 introduced the topic of online learning and reported using websites to access information relating to this caseload:

'..I've accessed mainly online training through the palliative care websites when I can..' (647-650)

P1 commented on the benefit of an undergraduate placement within HNC and discussed the experience gained, in a short time within this setting.

'..Learned a lot in a very short space of time..' (99-100)

P2 described post-graduate training in dysphagia some time ago but went on to report that as this was a general course, it did not consider anything specific to HNC.

‘..I can’t remember anything ever being specifically about palliative care in any context as an undergraduate..’ (884-888)

The focus group agreed that they had had little training in head and neck or palliative care/end of life care with this caseload and went on to discuss their perception of what is provided to current students.

FGB *‘..so they could go through training come out and not have considered this as an issue..’ (947-949)*

FGA *‘..It’s not enough dysphagia full stop never mind palliative care..’ (951-953)*

M1 also commented on current student training and reported having personally had no training in the area of HNC palliative or end of life care.

M1 *‘..there was no formal training..’ (644)*

‘..none I can answer your question none..’ (678-679)

M2 again reported little preparation for working in end of life and reported a perception that there was an expectation that SLTs would undertake this type of work without training. M2 also appeared unsure what was available in terms of current training:

‘..nothing six hrs of dysphagia is wholly inadequate to prepare you to even ..taking a case history for dysphagia I think..’ (676-680)

‘..I can’t believe that it’s different now because ..I cannot see how you can fulfill the needs of dysphagia even at an awareness level in one module..’ (684-690)

M3 and M5 too, reported little training and went on to discuss generalising skills from other areas into HNC:

M3 *‘..I don’t think we have very good training...I don’t think we have very good training..’ (795-798)*

(re eol training) *‘..I think we ...generalise our knowledge from all of our clinical knowledge into palliative care and end of life care and in some ways ..maybe that’s appropriate..’ (808-813)*

'..I actually cant..I can't remember any under graduate eol training I'm pretty sure it must have been there but I don't remember it ..' (868-872)

M5 *'..it was quite a while before I started working with erm end of life patients ...but having said that I had worked with non head and neck patients who were at that stage and so I think that experience was you could to transfer in some ways.'* (475-482)

'..If you're thinking training as in when I was a student no preparation at all..' (506-507)

M4 reported having had no specific training in this area:

'Erm' [sighs] 'I don't think I've had any specific training in terms of end of life..' (520-521)

M6 Further confirmed a sense of an overall lack of preparation in the following comments:

'.. we had nothing at all about end of life care it was acknowledged that our patients died but there was no training... how you would manage those situations..' (855-862)

Overall, most participants reported having had no specific training in HNC or end of life at undergraduate level. Only one participant reported having had placement experience for this caseload.

Comments regarding staffing numbers, appeared to relate predominantly to a view that increased staffing would allow more time to be spent with these patients and perhaps for services to be more accessible, or extended beyond the acute setting. P2 suggested a lack of certainty about what the demand might be for SLT services in end of life care.

- P1 *'...enough therapists..' (937-938)*
'..more time with them..' (970-971)
- P2 *'..I guess we would just need ...extra resources because..we haven't typically been involved at this stage I have no idea what the gap may be..' (1047-1050)*
- FGA *'..mm, I personally have to highlight that, our staffing isn't sufficient to provide a quality service to these patients because of the geography of where I work..' (1350-1355)*
- FGB *'..If you were asked if you are giving a good service what would your your answer be no...if the restrictions on our time..the geography etc we know that if these things were addressed and we did have more staff there the service would be so much better and we've highlighted that a few times..' (1364-1373)*
- M1 *'...they could be getting pleasure from some food and drink but they're not getting it because... the nursing staff can't cope with that kind of level of nursing so ..it just means patients being moved into hospice in a timely fashion ..' (854-859)*
 (re effective service needs) *'..enough therapists and an adequately funded service..' (968-970)* NB declined to elaborate
- M2 *'...I do think we are in a situation where the biggest professional issue is going to be training and the level of staffing that we have because this is a specialised area...' (1034-1038)*
- M6 (re home/hospice) *'..we're not particularly...I don't want to use the word staffed but I suppose that's what it boils down to the the kind of demographics of services generally I don't think just within this health board do not place Speech and Language Therapy in that environment to the degree that we probably could and we could be very effective in doing so..' (501-809)*

Whilst several participants alluded to demands, P1 specifically raised the issue of having other demands on SLT time aside from patient contact:

'..there's a lot of other stuff to do as opposed to just see patients..' (973-977)

Some participants raised the issue of multi-disciplinary communication and the need for more opportunity to liaise effectively, with other healthcare colleagues. Another aspect of MDT communication which came up, was the need to have all relevant members of the team both involved and informed about each other's roles.

- M3 *'...if you have good MDT communication and working relationships proper team participation...we need to fully participate in that..'* (1175-1180)
- P2 *'..if different stakeholders..involved in people at end of life knew that you were available for one thing ..'* (1016-1018)
- FGA *'..I think we need specialist palliative care teams and the SLT is one of the important roles..'* (1091-1092)
- P2 *'..perhaps being a bit more active within the MDT...discussing cases, bringing things up, initiating rather than responding...'* (1164-1168)

M1 also suggested a need to raise the profile of the profession and the potential impact this could have:

(response to probe attempting to clarify further) *'..yeah well I would like to be involved in the discussion about particular patients then we can make our own clinical opinion whether we should be involved or not..'* (1029-1033)

'..Yes so we can improve what other people perceive us to do with dysphagia..' (1135-1136)

P2's comments appeared to place particular emphasis on improving communication with the medical team.

- P2 *'..consistent ..efforts at being clear communicators good social relationships with other members of the team despite you know differences of opinion...'* (1157-1160)
- '..opportunity to have more face to face discussions with medical staff..'* (212-214)

Participants made a range of comments touching on a number of areas, including under-graduate training, workplace learning and ideas about formal training. There were also several comments about a need for professional guidelines.

The general consensus regarding under-graduate training was that there was a need for more information about palliative care, disease progression and the psycho-social impact of head and neck cancer, in order to understand the SLT role in these cases.

- M4 *'..it's probably helpful if at under-graduate level people were getting something about palliative care or...terminal illness and progression and how it can't necessarily need to be somebody dying tomorrow that it can be ...quite a long road..which is maybe a different way of thinking about things..to when I was at university..' (832-847)*
- M5 *'..I think training for students is so focused on this is the normal swallow, this is the mechanics of the swallow and this is what can go wrong and its I think there might be the occasional head and neck patient included in that there might be the occasional laryngectomy so they can understand the anatomy of that but I don't think it goes further than the structural I don't think it goes into the psychological side I don't think it goes into the end of life side I don't think it goes into [audible intake of breath] the support side of the patient and the family So that would be a starting point..' (704-715)*

Participants tended to view this area of practice as specialist, with several commenting on the need to retain specialist skills in this area in the future workforce. Specific needs related to an improved understanding of medical management at end of life as an aid to complex, ethical decision making, such as deciding whether or not to intervene.

Several participants reported the view that some sort of discussion group or online forum would be of benefit to working clinicians and there was a definite sense of a need to share and compare experiences, perhaps reflecting some degree of anxiety about management and decision making.

P1 suggested that this area of SLT requires specialist skills and discussed what training should include:

- '..it needs to be fairly specialist..' (997-999)*
- '..our understanding of how disease progresses..' (1000-1001)*
- '..structures that are affected..' (1002-1003)*
- P2 *'...I could imagine benefitting from ..additional training perhaps in some of the medical side of approaching end of life 'cause I would definitely be very limited in that..' (1067-1071)*
- M5 *'.. I think it would be good to have more specific erm I don't know if I'm talking erm SIG (specific interest group) type group.. it would be useful even periodically to have confirmation that what you're feel is right is acceptable practice for other therapists..' (718-727)*

M6 (re whether to see patient) *'..if we understood a bit better about just things like physiological change as the body shuts down and all the rest of it we might have a better idea of whether we should or shouldn't or could be making any difference..' (1257-1262)*

'..and again erm a better theoretical understanding about the process of the physiological process of dying and the issues around that medication and the influence all of that might have on where the patient's at and how the patient copes..' (1348-1360)

The focus group chose to expand their comments to discuss succession planning for the SLT profession, which appeared to be a key concern with regard to maintaining and developing specialist skills in the future workforce.

FGA *'..we need to continue the care for the patient at that stage, in addition to that its whether SLTs are trained and equipped with the exposure to be able to have the confidence to assess..' (1096-1099)*

C *'mm'*

A *'..and make these difficult decisions..' (1101)*

There were a number of comments suggesting that less experienced staff were voicing anxiety about entering this field of practice. It is unclear why this would be the case but the Focus Group participants implied some impact of early specialisation, perhaps reducing the opportunity to develop a broad experience.

B *'..the opportunity exists for them to have that guided experience but the time constraints on that are huge..' (1173-1175)*

A *'..thinking about conditions and not specialising too early..getting that exposure otherwise we end up with ...people who don't have responsibility for head and neck don't want to go into that area ..' (1182-1186)*

B *'..We need to stop making it a scary field to be going into..' (1187-1188)*

C *'...making sure people are aware how complex they are...I do think there are barriers put up and people are scared to go onto the ward...it's important that it isn't made complicated..' (1230-1236)*

Most participants were either unable to discuss existing guidelines or were unaware of what was available. P2, M1, M3 and M4 all reported uncertainty about access to guidelines and what the professional body of SLT, the RCLST could offer:

- P2 *'...I am never that clued up on what the Royal College can offer in terms of awareness raising..' (1106-1107)*
- M1 *'..I have to be honest and say that I haven't actually looked at the RCLST guidelines but I'm not aware of there being anything in particular..' (738-742)*
'...mm is it NES and that er the ..I can't remember what it stands for..' (re prompt about sources of information) (749-750)
- M3 *'..oh golly there are erm there are guidelines..care of the patient who is dying..I don't know I think they come from er NHS Scotland..I don't actually know..' (990-997)*
'..I know there are guidelines in ..England and Wales..well I think they're very similar but I haven't read them...I have read the guidelines for ..care of the patient who's dying. Within NHS Scotland..' (999-1009)
'..I guess there's maybe there will be I'm sure there's a section in communicating quality 3 but to be honest I ..just don't know ..'(1014-1017)
- M4 *'..That's a very good question and probably if I looked on the RCLST website there might be something..but I honestly I haven't..' (571-574)*

Both M5 and M6 appeared more confident about how to access information from the Professional body, library services and via the internet.

- M5 (re any resources specific to SLT in eol) *'..no not that I'm aware of..' (571)*
'..if needs be I would possibly go to college' [referring to RCLST professional body] '..and college advisors..' (513-514)
'..yeah I would go to college I would erm the library here are very good for getting articles and you could borrow either from here or through erm the university library..' (557-562)
- M6 *'..I would probably refer to RCLST guidelines erm because there there is a section within communicating quality on that erm well on on head and neck of cancer..' (907-911)*

'..SIGN guidelines would be worth a look as well.. I would look at the head and neck one..' (913-916)

'..I would probably speak to erm a member of staff a senior member of staff who was until very recently was a Royal College erm advisor in dysphagia and also who has a head and neck background erm so I would expect that she would be up to date with any new guidelines coming out in preparation or recently released just in case I'd missed something..' (918-928)

'..I would probably trawl on the internet as well other countries to see what guidelines there were in other places for example Australia and America. just just to see what they were doing..' (930-936)

In spite of this apparent lack of access to existing resources and a lack of seeking information, there was consensus on the need for additional information and guidelines.

M1 *'...I don't think enough is in place I think we need to do more definition of what our role is . . .I'm not even clear what my role is sometimes..' (1165-1169)*

'..So I think there should be a clear definition of what we...can do and what we can't do erm more training to help Speech Therapists support patients end of life..' (1171-1177)

M3 *'..arguably ..some more training ..an opportunity to..discuss and share maybe share practice..that might be..quite useful..that can be something that can be done within a SIG..' (referring to RCSLT Specific Interest Group) (1182-1189)*

M4 *'..I think we should probably have a broad definition of what our role would be within palliative care because again it's not necessarily going to be the same within different client groups let alone with different patients..' (815-823)*

'..the RCSLT I guess and I haven't looked so I couldn't honestly say that they aren't already doing something like this but presumably that should be where these kind of guidelines and focus groups are all initiated because they're our professional body and ..they do provide ..the guidelines on everything else so maybe they should be doing something similar for palliative care..I haven't honestly checked..' (864-877)

M6 *'..so better erm better guidelines better availability of guidelines and more widely understood guidelines would be really really useful..' (1398-1402)*

In summary, responses to the question of what was needed fell into a number of key areas: staffing numbers, demands outside of direct patient care, multi-disciplinary communication, including profile raising and presence within the team for SLT as well

as training needs, including a need for professional guidelines. Finally, service issues related to succession planning and the timing of specialist development, were also broached by participants as areas of need.

Not an all or nothing - changing landscape

There were some comments from the focus group and participants P2 and M3 in relation to change within the SLTs own views and changes within the wider team and the SLT profession. A comment from C within the focus group relating to the development of both the team and the SLT profession was felt to encompass the sense of all comments:

FGC *'..it's not just from the wider team I think as a profession speech therapists have now changed to look at the risk and managing the risk...not an all or nothing..'*
(766-772)

P2 *'..I think things could change as part of a..general raising of our profile within a MDT...I hope that's an ongoing thing..'* (1141-1143)

'..it goes hand in hand with a greater understanding within the MDT of what we can offer..' (1146-1148)

'..so I think if people start to understand more that we can advise and educate and support through all stages then that may well ...change how we're involved with people at eol..' (1151-1155)

M3 *'..if you have good MDT communication and working relationships proper team participation...we need to fully participate in that..'* (1175-1180)

The focus group and M4 also touched on wider aspects of change making reference to an ageing population and resultant issues such as an increasing demand for end of life care and increasing shared working practices.

M4 *'..because of the way treatments have progressed there's probably going to be a lot of people who are living with a terminal illness or longer..'* (558-562)

FGA *'...many years ago consultants never liked to manage things in that way, I think they now see the benefit because patients are living longer we have got more of*

them to cope with and they are handing over to AHPs and clinical nurses..'
(712-719)

FGB *'...I don't think it's just experience I think the involvement of SLTs in DG management has developed so much within the past 20 yrs even 15 yrs...with palliative care...then we are more working within the team..'* (745-752)

Summary of Findings

The findings resulted in four super-ordinate themes which were examined in detail. '**A risk worth taking**' presented participants comments concerning how they viewed the clinical area, the patient group, their role and main aims. '**Under your skin**' introduced participants comments about the emotional impact of this area of practice.

'**Communication isn't always wonderful**' focused on multi-disciplinary working and '**Trained and equipped**' presented participants comments about preparation and training for working in the field of end of life within HNC, as well as their views on what was needed. The next chapter will discuss the findings in relation to the research question, the theoretical framework and the wider literature.

5 Discussion

This chapter considers the findings in relation to how well they are able to answer the research question, through the lens of the chosen theoretical framework of Bronfenbrenner's ecological systems theory. The findings are also examined in the context of new literature.

The main aim of this study was to explore the experiences of SLTs in delivering end of life dysphagia care to adults with head and neck cancer. Additionally, the study aimed to provide a basis for supporting the development of future SLT education, by identifying SLTs experiences of preparation for this role. The final aim of the study, was to contribute to the SLT profession's ability to meet the needs of SLTs by identifying what they thought was required to provide this care effectively.

The research question asked:

What experiences do SLTs have of preparing for and delivering end of life dysphagia care with adult HNC patients and what do they think is needed to provide it effectively?

Four super-ordinate themes were identified from the data. These were:

- A risk worth taking
- Under your skin
- Communication isn't always wonderful
- Trained and equipped

In the following section a broad discussion is provided in relation to the application of the theoretical framework of Bronfenbrenner's ecological systems theory. The findings are then considered in the context of additional new literature.

Application of Bronfenbrenner's ecological systems theory

This theory and the rationale for its application was discussed earlier (pp 20-24). Here, it is discussed in terms of its application to the findings and overall utility.

The microsystem

This sphere of the ecological system relates to the immediate home context with direct relationships between family, friends and in the case of this study, workplace peers and colleagues. The microsystem concerns the individual's direct, close experiences.

Participant comments regarding their perceptions of 'giving permission' to take a risky decision could be considered within the microsystem. Perhaps those participants who viewed their role in this way were reflecting their own personal values and experiences in framing their role in terms of the need to provide approval for patient decisions.

Equally, the views expressed regarding this type of dysphagia care being 'different' may also reflect the individual participants perception of what is considered to be routine dysphagia..

Other examples from the data suggest that the views expressed around being unable to 'fix' issues, dealing with younger patients, fear of the area, dealing with dying, reflections on differing personalities and the burden of guilt would lie within this sphere. It is suggested that some of these issues could lead to differing experiences of development within the next sphere the mesosystem. The mesosystem, in the case of this research might relate to the workplace. Perhaps some of these individual beliefs may have impacted on how participants experienced workplace issues. An example might be P2 who had expressed a view that the participant's personality might not be suited to this kind of work. It could be the case that this assumption may have impacted on how P2 approached workplace issues such as whether or not there was a role for SLTs in end of life care.

The participants perception of their clinical recommendations being changed may serve to demonstrate the impact of the microsystem on individual participant development in the workplace. Some participants expressed frustration at this issue without suggesting

any resolution, others explored why these issues may be occurring and offered potential solutions such as increasing presence to improve awareness of the SLT role and contribution. These differing approaches may have been influenced by the individual participants own experiences in terms of exposure to problem solving or having more of a sense of personal responsibility to improve the issue than others.

Participants description of their current post and level of experience as well as the comments regarding changes in their personal views could be considered to form part of the microsystem. Those participants with less experience of working in head and neck cancer reported some different experiences than those who were engaged in this area of practice more frequently (e.g. in P1s comments about being able to 'fix' issues).

Comments about perceived workplace hierarchies could also be viewed in relation to the impact of the microsystem on the mesosystem in terms of how some participants viewed the workplace and the relationships within it.

The mesosystem

The mesosystem concerns the interaction between the microsystem and the wider context influencing participants, in the case of this study this would relate to the workplace in terms of relationships, interactions and working practices. Some of the comments around levels of experience, current posts and shared working practices could be considered within this sphere. The focus group introduced the topic of working with less experienced colleagues where they expressed a view that perhaps these staff made more cautious recommendations. The focus group went on to suggest that this required support from more experienced colleagues to develop less experienced staff towards a broader view of clinical decision making.

Comments about the impact of setting, being over-ridden, other demands and the need for support could also be considered within the mesosystem in that they all relate to the workplace in terms of relationships, workplace environment and expectations driven by the nature of the working environment in terms of communication and workplace culture.

There were a number of comments about how participants learned including on the job learning and workplace learning. These areas might also be considered part of the mesosystem of the workplace since they reflect the impact of participants personal experiences on their reported workplace activities.

The exosystem

This wider sphere within Bronfenbrenner's theory can be applied to consider influences such as policy, funding, transitions within healthcare and professional issues. Examples of data relating to the exosystem could include the comments about the aims of the role, definitions of terminology, the perception of risk and the views regarding dysphagia being different. All of these comments have a relationship to the wider issue of professional support and development. It could be argued that the participants professional development could have been more robustly supported had there been clear professional guidance outlining expectations and strategies to employ in dealing with these cases.

Comments regarding the fear of litigation, patient transfers to hospice and their perceptions of risk management could be considered to relate to how well prepared participants felt about the area of work. This has a direct relationship to the professional issue of preparation, policy and educational resources. Had the participants reported that they felt prepared and had received adequate input regarding available resources and professional expectations, perhaps their perception of risk and fear may have been viewed more holistically. Their perception of risk may not therefore have been as prominent when viewed from within a visible professional framework. In addition, some of the comments about setting, support and staffing may reflect issues around workforce planning in terms of what was considered necessary to provide an effective service in terms of both costing and staff support structures.

Participant comments about difficulty attending ward rounds could fall within the mesosystem related to ground level workforce planning and also within the exosystem in terms of broader local funding decisions influencing staff coverage and availability e.g. if some staff were required to provide input to multiple sites this may have

impacted on their ability to integrate with the wider team. Equally participant comments about difficulties in accessing medical staff may relate to the exosystem in that if the medical staff were required to provide cover for unplanned events or unexpected sickness this could impact on visibility and communication with the wider team

The wider exosystem is also exemplified in participant comments regarding having other demands, accessing professional guidance and the influence of the setting. These comments reflect local working practices with regard to how staff are deployed and what methods of learning are facilitated.

The macrosystem

The macrosystem concerns the widest sphere of influence such as Government policy, population change etc. Comments regarding an ageing population could be aligned to this sphere of influence. In addition, comments regarding the type of patient may also link to this sphere in terms of the impact of new treatments such as organ preservation and targeted treatments resulting perhaps in the maintenance of a higher level of functioning for people with this disease for longer, thereby allowing them to make their views and preferences known more readily than in the past.

Issues such as NHS funding and broad workforce management approaches could also be viewed as part of the macrosystem, These aspects may have directed the position with regard to workforce planning and therefore influenced staff access and availability.

Finally, participant comments suggesting their view of a changing professional landscape could be considered to align with Bronfenbrenner's macrosystem since these comments demonstrate how wider less direct influences can exert an impact on the individual.

Reflection on the application of Bronfenbrenner's ecological systems theory as a theoretical Framework

Overall, whilst Bronfenbrenner's ecological systems theory has its limitations perhaps in its perceived emphasis on context, it was felt to have provided an effective means of considering differing levels of influence within and between participants. In addition, the flexibility it afforded in terms of the ability to consider the same data in different ways proved a valuable tool in ensuring the analysis was firmly rooted in the generated data from participants. This is exemplified in the comments about the difficulty in attending ward rounds which could be viewed from both the perspective of the mesosystem and the exosystem and even perhaps the macrosystem. This feature of the theory provided a means of viewing multiple aspects to the data which, along with the necessity to return to the data multiple times, afforded different participant perspectives rather than any fixed single interpretation on the part of the researcher.

Application of new literature to the findings

Perhaps one of the most striking findings of the study, was the significant emotional impact that was implied as a result of working in this clinical area. The pre-study literature had not fully revealed this issue in relation to SLTs. The flexibility designed within the interview schedule, allowed this theme to be revealed from the data, having been introduced by participants in the course of the interviews. There is however, literature concerning this issue in relation to other professional groups.

Wilson and Kirshbaum (2011) conducted a literature review and thematic analysis of thirty-three articles from peer reviewed journals and grey literature, into the impact of patient death within hospital settings on nursing staff. The search focus was on reports of detrimental effects and support structures. The authors concluded that the literature highlighted the existence of an often negative, emotional impact on nursing staff. Wilson and Kirshbaum (2011) concluded that the literature demonstrated that this impact was influenced by workplace culture, personal circumstances, education and the age of the patient. Although this was a small literature review of mainly quantitative

research (which the authors recognised), it does suggest that an impact on other healthcare staff has been identified which may be echoed for SLTs.

Spidell et al (2011) conducted a survey of healthcare chaplains in the US. Whilst the survey was widely shared (three thousand plus issued) they achieved only an eighteen percent return. However responses demonstrated that twenty-one percent, reported feeling unsupported in the workplace with regard to dealing with death and suggested a need for further examination of this area for chaplains. Again, this would suggest that the emotional impact of patient death on healthcare workers, has been recognised for other professions but perhaps not yet fully for SLTs.

The interview prompts which enquired about difficult issues and challenges, generated some of the most notable comments in the whole study, suggesting that this was an area which required further consideration for these participants.

P2 talked about difficulties experienced when attempting to broach sensitive topics such as a changed prognosis, when the patient was housed within an open ward. This was expressed in terms of a concern with having to choose words carefully, without becoming unclear or alarming those nearby. This suggests that the impact on the SLT and perhaps also on the patient, may have been changed as a result of the setting in which the patient was seen. If the SLT was cautious and selective in their language due to a concern with others hearing, this may have been perceived as more alarming to the patient than a more openly, transparent discussion.

In terms of application of Bronfenbrenner's ecological systems theory, this would align with the notion of a mesosystem being impacted upon by the wider exosystem in that the nature of the wider environment appeared to impact on the individual and their behavior according to where the interaction took place, with increased emotional impact appearing to be reported in open, less private settings, over which the SLT would have little control.

M1 raised the issue of perceived barriers, related to delays in moving patients from the acute setting into the hospice setting. M1 perceived this as being linked to the level of complexity of care required e.g. head and neck patients with tracheostomy tubes. This participant was of the view that such cases may come to spend more time within the

acute setting, due to some lack of specialist support within the hospice. This again would resonate with Bronfenbrenner's theory in that the wider exosystem of transitions between healthcare settings appeared to be impacting on the immediate situation for the participant.

M3 discussed experience of cases where the perception was that complex head and neck cancer patients sometimes preferred to remain within the acute setting, as they had built up trusting relationships with the staff there and as a result, felt safer staying with what was familiar. It is unclear whether these reported perceptions are truly representative of the wider picture, however if it is indeed the case that some patients are remaining within acute settings when they would prefer to or should move to a hospice, then there is clearly further work to be done to ensure prompt, patient centred transitions between care settings. This would also support the Scottish Government's agenda for shifting the balance of care by providing more care outside of acute settings (Audit Scotland, 2016)

Bronfenbrenner's model can again be considered in relation to this aspect in that if it is indeed the case that some patients felt safer within the acute setting, then the perception of the wider exosystem appears to be influencing decisions within the individual patient.

Some participants (M1, M6) commented that both patient care and multi-disciplinary working, was more effective in the hospice setting compared to acute. If this is the case, then there may therefore be some benefit in closer working between hospices and the acute setting in Speech and Language Therapy. Perhaps some examination of cross fertilization of working methods may be indicated, to improve both equity and quality of care. At present, there is no clear data on how many SLT services provide a service to hospices or what the nature of that input is. Perhaps there is a place for exploring this further in a future study, with a view for making the case for a more integrated role in such settings across the profession.

Several participants introduced some discussion of the impact of feeling unable to resolve swallowing problems, particularly P1 who mentioned 'fixing' several times and was quite new to the role (with less than six months exposure). Unfamiliarity with the

expectations of the HNC and end of life caseload, may have impacted on this participant's perception of what was a realistic goal for these patients.

The focus group and M4 appeared more reconciled with the idea that nothing could be done but they still reported a sense of '*feeling a bit helpless*' and in the case of M4, a desire to solve the issue. This appeared to reflect a sense that some SLTs perceived their role as relating to resolution rather than management or mitigation. Working with people who were not expected to improve, may have resulted in some conflict with the traditional sense of the SLT role as being rehabilitative and working towards an expectation of improvement, which may explain some of the discomfort expressed in managing these cases.

This tension between rehabilitation and palliative or end of life care was revealed in the initial literature search. The work of Robin Pollens proposed that some clinicians might take the view that rehabilitation in end of life care may be inappropriate and suggested that there is a role but also a need to clarify what that role is (Pollens 2004). She returned to the topic in a later paper (Pollens 2012), with an urge to SLTs to integrate more within the palliative care team in order to establish clarity of role.

In terms of the broader role and the need for participation within the palliative and end of life team, the findings would also support the work of Buck (2013), Groher and Groher (2012), Macmillan (2011) and Newman (2009) and who supported the role of both AHPs and SLTs in end of life care. A number of other studies included varying degrees of discussion of this issue, including Biddle and Mitchell (2008, Langmore (2009) Roe (2007), Roe and Leslie (2010) and Toner and Shadden (2012) all of which supported the inclusion of SLTs in the palliative and end of life team.

It would seem that the findings of this research bears out these views, in demonstrating some apparent uncertainty in the participants about their role and level of inclusion within the multi-disciplinary team within end of life head and neck cancer care.

There is a clear discomfort in some participants related to dealing with patients in a similar age group to themselves (P1, M2, M6). Younger cases tended on the whole to

form the basis of most of the accounts of the most memorable cases, which may represent the impact these cases had on the participants. Perhaps this type of situation makes it more likely that the SLT will identify with the patient as a peer and may therefore reflect the SLTs need to come to terms with their own mortality. This may be a source of discomfort for those who have not ventured to consider such issues.

This is not a new idea but has not been fully explored in relation to SLTs. Kubler-Ross and Worden (1977) discussed this issue in an early paper reviewing attitudes and experiences of death workshop attendees, concluding that some healthcare staff expressed increased difficulty in dealing with patients of a similar age and gender.

M6 was the only participant who attempted to suggest why this might be the case for SLTs, in discussing a possible empathy in seeing someone of a similar age going through cancer treatments, whilst the remainder mentioned the issue but did not attempt to elaborate on the reason for it. In terms of Bronfenbrenner's theory this would align with the individual's microsystem of personal experience and relationships impacting on the mesosystem in that participants were perhaps relating their own peer experiences with that of their patients.

The duration of contact with these patients and the reported often lengthy, relationships also seemed to have some influence both on the emotional engagement with the patient and on how readily the SLT felt able to broach sensitive topics for discussion (P1, M1, M2, M4, M6). Participants P1 and M2 clearly enjoyed this aspect of the post, with M2 appearing to express this as facilitating a more open dialogue. As with P1, M1 made reference to a long patient journey, which appeared to have resulted in a feeling of legitimacy in being able to discuss sensitive issues more readily. There were also comments from M3 suggesting that a long patient relationship enabled the SLT to broach more sensitive conversations about prognosis more readily.

This lengthy relationship seemed to affect participants, in that they not only saw the changes occurring over time but also saw this within an established relationship. This suggests a longer term, closer engagement with clinical cases than perhaps might be the case in more straight forward rehabilitation therapy. Wilson and Kirshbaum (2011) discussed this issue in relation to nursing staff, suggesting that nurses were a group

who had the most contact with patients which resulted in the formation of strong relationships. This appears to be echoed within the SLT data. Perhaps the depth of relationship resulted in increased insight into the experiences of those patients with whom it was shared, thereby adding to the emotional burden for the SLT.

Both of the above issues (cognitive ability and length of relationship) appeared to have played a significant role in influencing how SLTs reported what it felt like to work in this area.

It may be worth considering whether decision making is more difficult for the SLT when the patient is able to fully engage in the process and the traditional paternalistic 'let the healthcare professionals decide' is less evident. Perhaps some participants find vocal and cognitively able patients more of a challenge to advise, particularly if they wish to discuss the rationale for the SLTs advice.

P1, the Focus Group and M6 discussed their perceptions of how they themselves as well as other SLTs and students, viewed the idea of entering the field of both HNC/end of life. Language such as '*frightened*' '*hate to do it*' '*scary*' and '*terrified*' was used.

These comments are certainly of note, exhibiting strong emotional language which is marked within this dataset, but it is unclear how representative they are for the wider professional group. If there is a wider degree of anxiety about entering the field of head and neck cancer and end of life care, then this would suggest a need for the profession to consider how this might be addressed to ensure adequate preparation for SLTs as a priority. This would need to include some consideration of future curriculae and workplace induction programmes for new graduates.

Comments regarding being over-ridden, arose from a number of participants. P2, the Focus Group, M1, M5 and M6 all related accounts of having been over-ridden by consultant and MDT colleagues. This issue was not identified in the literature search which may reflect that this is not a general feature of this type of work or that it is perhaps going unreported, due to the sensitivity of the topic.

For P2 this appeared to be a frequent issue with a reported impact on job satisfaction. The comments about being over-ridden were a concern as they had the

potential to demonstrate that SLTs were not working well within the team or were failing to view cases holistically within the wider context and thereby deliver appropriate recommendations. They might also suggest that SLT input was not perceived to be of value, as suggested by M1 and P2.

Following deeper analysis, it seemed that the perceived lack of multi-disciplinary awareness of the SLT role as well as a lack of available professional guidance was more of a factor in this issue rather than a failing in the SLT contribution. This is considered in the discussion of the theme 'Communication isn't always wonderful'.

It seemed that SLTs were unsure as to how protected they were and what safeguards were in place when they were required to make high risk decisions, such as supporting someone to eat and drink when their clinical assessment had revealed a high risk of aspiration. M6 commented on the risk of litigation.

Complex, ethical decision making appeared to place the SLT in a position of increased risk with a need to ensure that decisions were fully documented and communicated thereby placing an additional burden on the SLT to protect themselves should any adverse events occur as a result of the patient's decision (FGA, M6).

There was a sense across the data that most participants had a concern about potential litigation or adverse implications of decisions although it was not explicitly stated in most cases. One might consider if this is perhaps because participants were of the view that stating such fears, might be considered unprofessional as it would place the primary emphasis on the SLT rather than on patient needs.

Within the data there emerged a sense that some SLTs seemed somewhat frustrated with patients who chose not to adhere to their advice (P2, M5). SLTs clearly need to be comfortable with accepting and managing patient choice readily. This raises the question of whether SLTs need to learn to be more comfortable with patient centred care, rather than being concerned with professional implications. In the Focus Group, C discussed a similar situation reporting on a patient who: '*..went off and did absolutely his own thing..*' (579-583). Miles et al (2016) explored perceptions of complex feeding decisions in a qualitative study based in New Zealand. The context included discussion of how best to support patients who wished to continue to eat and drink, where a risk

had been identified. They examined the views of patients, carers and staff, concluding that collaboration and communication were central to effective shared decision-making.

The SLT practitioner is required to consider the best evidence alongside the patient's wishes and to make decisions within their own sphere of professional experience and clinical decision making. In reality, whilst some people may in fact be able to manage more difficult foods, SLTs have to decide on what is the safest option to recommend within the acute setting. As a result, it might be the case that the most modified option (and therefore the one perceived to be safest) is recommended, in order to allow for busy nursing staff who may not have time to supervise those with eating difficulties. As diet modification is usually a short term measure, this is usually effective as the safest approach. It is possible that SLTs may tend to take the same approach to end of life care cases recommending the 'safest option'. This may be the case particularly with less experienced SLTs, who may lack the confidence to make choices outside the accepted norm or where the level of risk is increased. It is suggested that perhaps a different approach needs to be taken in such cases and that a different decision making process may be required such as consideration of the risk/benefit and timescale indicated in individual cases.

In these situations, it may be the case that some SLTs 'default' back to a decision making processes based firmly within the adult acute rehabilitation setting (e.g. P2 and M5 who both discussed 'compliance'). In this way they would revert to making 'safe' decisions such as requesting that the medical team consider a nil by mouth order or suggesting very limited food trials, similar to the approach taken on a fast moving acute hospital ward. In the acute ward setting, this type of approach is often the most appropriate as such recommendations are usually very short term e.g. two or three days before reassessment allows the recovering patient to gradually resume a more normal dietary intake. However, in the end of life setting, such radical limitations on dietary intake may not always be the most appropriate management since the withdrawal of food and drink or the removal of appealing options of diet may have a significant impact, both on the overall medical management e.g. by raising the ethical difficulty of non-oral feeding discussions, but also on the emotional wellbeing of the patient and their family.

Often the only remaining care giving left to families is to offer small amounts of food and drink and when this is removed the impact cannot be underestimated. It would seem therefore that there is a need to put in place support to acknowledge that dilemma and to recognise that in some circumstances, more risky approaches can be considered to be a legitimate method of management.

This again, may reflect a sense that the SLT is concerned with ensuring that they are leading the care and managing professional risks, rather than the patient's wishes being the primary concern. The question of whether SLTs are at times making choices which sit more comfortably with them than the patient should also be considered. The SLT can sleep at night if they know that the patient is not at risk but one might ask whether there is an impact on the patient of such cautious decision making.

This reflects the position as stated by Stranberg et al (2015) who, in examining risk decisions around nutrition, took the view that there is a need for increased communication across the multi-disciplinary team, including with SLTs when it comes to making such sensitive ethical decisions. It may therefore be the case that the SLT profession needs to consider risk decision making processes more fully.

In terms of Bronfenbrenner's theory this would align with the wider exosystem over which the individual has little influence, impacting on their experiences at the lower levels. The inner microsystem may also be impacting on the individual's response to the situation, in terms of their fears manifesting in changed actions within the mesosystem of the workplace.

M3 introduced a discussion of the approach taken to dealing with a new experience i.e. a first visit to a hospice and the impact this had on the participant, in terms of how to approach working within this new environment. This raises the question of how SLTs are supported to deal with patient death. There were very few accounts of actually dealing with patient death throughout the interviews, apart from M2's moving account of having the opportunity to say goodbye although most SLTs were able to discuss their involvement in end of life care.

FGC commented on it being '*bad news all the time*' (1294-1279) which suggests some sense of the pressures of this field of work, where progress may be limited or not expected at all.

M6's striking comments about coping with these situations perhaps indicated the difficulties in managing this caseload (626-632). M6 whilst having significant experience of the caseload also implied that coping strategies can be variably successful in stating that some cases '*get under your skin*' (626-632).

The strength of emotion in this participants comments in this respect was marked and suggested that this participant had strived to find a way of coping with working in this emotive clinical field.

M2 provided an illuminating view of how the pressures of the caseload affected this participant, with an emotional account of the impact of a perceived accumulation of negative events (388-399). This participant later went on to describe how support is accessed but it would seem that working in the field of end of life had a significant impact on some participants, particularly those individuals regularly engaged in such work.

Both of the above sections beg the question of whether there is an unmet need for the profession in this respect. They also resonate with the findings of Chapple et al (2015) who in discussing issues around difficulties in talking about certain types of death, included an account of the concept of the 'death taboo' which asserts that death remains a topic which is not openly discussed. Doka (1989) also described the term 'disenfranchised grief' which he asserted was applicable to those situations where it was not considered appropriate or necessary to express grief. This could be applied to the above professional situations, where perhaps SLTs may have felt that such expressions would not be expected from healthcare professionals. It could be argued that if such a situation existed for the participants, this would add to the emotional burden for them in being unable to discuss the impact of patient deaths.

Coping with such difficult issues may come more easily to some than others and may therefore be a source of additional pressure for those working in this field of practice. P2 volunteered a personal account of discomfort with the end of life group and a

preference not to be involved as well as difficulty in knowing how much to say, but reported being unsure why this was the case. This may have impacted on the participant's perception of the caseload as a whole and on the participant's interactions and communication with both patients and colleagues. This may account for the slightly anomalous nature of this participants comments in terms of the intensity of emotion conveyed across the transcript.

This can be directly related to Bronfenbrenner's theory as it appears to relate to the individual's personal experiences within their microsystem impacting on their experiences of the mesosystem. This may be influencing choices, decision making and professional development for the participant. One might also consider whether the notion of systems seeking equilibrium could be applied at an individual level. Preferring to remain within the participant's familiar, professional comfort zone could be a manifestation of such personal, equilibrium seeking.

The comments in this area seemed to relate both to recognition of the significant impact of withholding food and fluids on the patient and to a sense of anxiety about the decision to do so. This apparent anxiety is perhaps linked to a concern about whether it was the right decision or if another SLT might have taken different action. Additionally, in the Focus Group, C expressed how certain cases '*preyed on your mind*' due to the level of risk in the decision taken. This is a considerable burden for the SLT and represents a further case for the need for professional clarity of roles and responsibilities as well as safeguards which will be discussed further in the theme 'Trained and Equipped'. Hersh (2010) touched on this topic, in her paper which explored the impact on SLTs of ending the therapeutic relationship, suggesting a marked emotional impact including feelings of guilt and sadness, particularly in those cases perceived by SLTs to represent a lack of achievement of intended outcomes. The participant's beliefs about healthcare and death may have influenced their perceptions. This could again be viewed within Bronfenbrenner's theory as the microsystem impacting on the mesosystem.

Overall, across the data, SLTs actively sought and voiced that they required support from their colleagues through a variety of means, including shared cases, team discussions, shared learning, senior support and multi-disciplinary learning. This seems to indicate not only a need to have the opportunity to share difficult experiences and complex cases, but also a need to gain a sense of reassurance of having done the right thing. This might reflect a wider lack of professional clarity about the role and what is considered appropriate practice as previously discussed in relation to the literature.

The degree of emotional impact on participants was marked and appeared to be a significant issue within this dataset. Responses regarding coping strategies and emotional burden were striking. This topic ultimately came to take up a significant place in the overall findings and ultimately in the recommendations of the study.

Issues with MDT communication were recognised in the literature, in terms of SLTs not being fully integrated into the palliative care team (Eckman and Roe 2005). However, the data revealed some specific issues with MDT working beyond what was evident from the literature at the outset. Specific issues highlighted included a perception of being overridden or having SLTs recommendations changed by other professionals, predominantly medical staff, as illustrated most notably by P2 but also mentioned by the focus group. Tabak and Koprak (2007) examined conflict resolution between nurses and doctors in relation to stress and job satisfaction. Although they described existing issues with subordination and hierarchical relationships, they did not examine specific types of conflict. Indications of which situations resulted in conflict would have been of interest. The authors did however, suggest a need for conflict strategies to be included in nurse education which may also resonate with the SLT evidence in this research.

A number of positives of multi-disciplinary working were revealed from the data, including being part of the team and being known on wards. This was expressed as in contrast to typical acute working in the experience of the participants, where perhaps several staff might cover a wide range of wards across a working week. Participant P1 appeared to suggest that multiple staff visiting wards potentially impacted on how easily relationships were built and maintained with ward staff. This participant was new

to the area of work, having previously worked on mainly routine acute wards. In a similar vein, Haggerty et al (2013) examined continuity when care is provided by multiple staff from the patients perspective. The authors discussed three types of continuity: informational, management and relational continuity. They suggested that maintenance of these supports both team continuity and the patient's experience of security and confidence in healthcare.

The opportunity for liaison, support, shared decision making and learning about other staff roles as a result of the necessary close multi-disciplinary working within the specialist field of head and neck cancer, was also viewed positively. The opportunity to be involved in team meetings such as discharge planning and multi-disciplinary team meetings was seen as being of benefit, with some participants stating that this had provided a basis for considerable clinical learning within the workplace (e.g.M3).

In addition, M3 stated that as a result of this working practice, this participant felt more able to open up difficult discussions within the team and raise issues for debate.

M5 commented on a positive relationship with Clinical Nurse Specialist colleagues, who were viewed by the participant as providing a first point of contact and a prompt source of updates.

Overall, there were many positives about this method of working practice which appears to endorse the approach for SLTs.

Comments from the participants in this study were in agreement with the need for strong multi-disciplinary team working which appears to align well with the existing literature on the topic (Biddle and Mitchell 2008, Eckman and Roe 2005, Groher and Groher 2012, Levy et al 2004, Licitra et al 2016, Pollens 2004, Pollens 2012, Roe and Leslie, 2010, Toner and Shadden, 2012,)

There were a number of comments relating to perceived inadequacies in participants experience of multi-disciplinary working. The most significant comments concerned working with medical and consultant colleagues in particular. This issue was discussed in the earlier theme 'Under your skin' but is also discussed here from the perspective of

communication. There was a general consensus that fellow professional groups have a poor awareness of the SLT role in end of life care.

Some participants suggested that the SLT profession had a role to play in addressing this perceived inaccuracy (M6, P2), whilst others expressed frustration without suggesting a solution (M5). This perception of poor awareness, also resonated with comments referring to a perception that SLTs were not needed at this stage of care and that as a result, referrals were not made thereby impacting negatively on access to SLT advice. M5 commented on feeling 'at the end of the line' (819-824). Access to medical and consultant colleagues was raised with some participants suggesting that it was difficult to have face to face discussions about case management (P2).

This echoes comments made by Salt et al (1999) who discussed a view that there was limited access to SLT for brain tumour patients. Fortunately, this situation now appears to be changing with these patients with increasing SLT presence at an earlier stage of care as reported by De Witte et al (2015) in their discussion of awake craniotomy procedures where the SLT assumes a key role in the procedure monitoring language function as the procedure is conducted. This was discussed earlier in section 2.2.2.

There was some recognition in the initial literature that AHPs were not well represented as core members of most multi-disciplinary palliative care teams (Newman 2009, Pollens 2004, Pollens 2012, Waldron et al 2011). The findings of this research would seem to support and extend this in the comments about access and poor communication.

Inappropriate re-referral was a topic raised by P2, who took the view that this was a poor use of the SLTs time. It would seem that there is a need for wider education of referral agents to enable the most effective services to be targeted at the most suitable times.

However, in view of P2's disclosure of a personal discomfort with the end of life caseload, it is possible that P2 may have preferred not to be involved or may not have considered other approaches to management and that in fact the re-referrals were appropriate but this participant did not yet have the therapeutic 'tools' to recognise this.

M6 introduced the subject of culture into this topic, with the suggestion that the acute setting represented a hierarchical culture with the consultant at the top and little opportunity to influence this established system. This issue was reported by Mackintosh and Sandall (2010) who described hierarchical working practices in emergency healthcare situations and suggested that these issues could be ameliorated with the use of standardised communication protocols. It would be disappointing, if it is in fact the case, that in the twenty-first century NHS workforce, historic, hierarchical cultures continue to prevail.

M5 offered a view that communication was more effective when the patient was more vocal (827-836). If this is representative of the situation overall within head and neck cancer care, it may signify some degree of potential inequity in clinical care. This would be unethical and not desired practise. This perception, however was not shared across participants.

The initial literature search had noted the lack of inclusion of SLT issues within some studies with a medical focus (Cinocco 2007, Gillick 2009, Kaldjian 2009, Lin 2011 Sciubba 2009). Literature within other professions and other countries had however highlighted some development towards improvements in shared working Guru 2012, Payne 2011, Vitale 2011, Waldron et al 2011.

Perhaps this reflects a need to further develop communication and shared understanding between the two professions, within end of life head and neck cancer dysphagia care. The data in this study would seem to suggest that this is indeed the case.

In terms of Bronfenbrenner's theory this might be equated with the exosystem and macrosystem impacting on the individual in that organisational structure and workplace culture may be influencing team communication and service delivery decisions

In summary, the data appears to demonstrate that there is some way to go before SLTs are routinely included in all MDT working and before equitable access to SLT advice is achieved.

The literature suggested a need for further training for SLTs (Roe and Leslie 2010, Toner and Shadden 2012). The data, however, revealed a sense of a distinct lack of preparation in most cases particularly at undergraduate level which was not evident from the original literature review.

Literature from other professions also suggested a need for further educational provision (Carrasco et al 2015, Glascott et al 2012), which may indicate that the issue of adequate preparation for this area of work is not confined only to SLTs.

The level of dissatisfaction with some aspects of educational provision was striking. The data revealed a consensus that participants felt unprepared for this area of work. Although they were able to discuss a range of methods of learning, this related mainly to workplace learning, either individually or in some cases with peer or senior support. Some participants had accessed external training but the general consensus was that none of those interviewed had attended specific specialist training targeted at the needs of SLTs. Only one participant had had the opportunity of under-graduate placement experience with this group (P1), which the participant viewed as a positive experience.

Most participants viewed undergraduate and post-graduate preparation as either non-existent or inadequate. In fairness, all participants had been working for a number of years, however, informal discussions with local Higher Education Institutions during the planning phase of this project and during the final stages, revealed that no current programmes were in place.

Access to hospice based training was viewed positively by some participants (M2, M6), whilst others reported feeling that it was not specifically what they needed (M3).

Participants appeared unsure of the availability of current training opportunities, with FGC suggesting that little external training had been available until recently (898-904). Equally, several participants were unable to discuss available guidelines, with some stating that they had not looked (e.g.M3). It is unclear why participants would not seek to access this information. It may be the case that the participants were in fact accessing other resources, such as online, professional learning rather than specific guidelines. Either way, in the drive towards evidence based practice, there is a need to

ensure that professionals are able to access evidence based materials readily. Presumably, if SLTs were able to access profession specific training and guidance, this might also help to equip them with additional resources to utilise when dealing with such challenging cases.

Although the initial literature review found little detail or evidence of inclusion within available recommendations (NICE 2004, RCSLT 2005, 2006, 2006, SIGN 2006, Scottish Government 2008, RCSLT 2009) there were indications of a changing picture with increased recognition and inclusion of the SLT role (Health and Social Care Information Centre 2009, 2012, 2013, NCAT 2009, 2012, 2013).

There are increasing attempts to address the profession specific issues such as the work of Mathisen et al (2011) who conducted a pilot exercise to educate SLTs in palliative care and more recently Ray et al (2014) who reported on the use of video-conferencing in order to provide palliative care education in remote areas. The RCSLT too is now addressing palliative care within the profession with the ongoing production of online clinical resources which will include palliative care (RCSLT, 2016).

It is hoped that the Scottish Government's Framework for the delivery of palliative care (2016) will also result in further development as a result of its intention to explore the current workforce skill base and educational requirements, as well as recommending wider professional inclusion. The development of a Scottish palliative care research forum also forms part of the intended remit of this framework, which may afford the opportunity for SLTs to become more engaged in future guideline development.

What is needed?

The issue of staffing was raised by the Focus Group, P2 and M6 with a sense that the participants felt that current staffing levels were insufficient to provide the level of input required for these cases. P2 also suggested a need to consider what the demands might be of taking on this area of work.

There is a sense of the need for SLTs to be considered part of the end of life team. The need to raise the profile of SLT fell within these comments, suggesting some onus on the profession itself to improve communication, awareness and presence within the team.

With regard to preparation, the findings would suggest a need for under-graduate training to include some aspects of how disease progression impacts on care, psycho-social aspects of head and neck cancer, palliative care principles and ethical decision making. Participants expressed a desire for post-graduate training to be specialist and to include medical management and issues specific to the SLTs requirements.

There is a growing debate in the literature around the issue of oral feeding in the face of known risk, which suggests that the SLT profession needs to address this issue. This was identified in the initial literature review. Groher & Groher (2012) suggested that this ethical dilemma is mitigated with appropriate shared communication, regarding the risks and benefits of oral feeding. Stranberg et al (2015) explored risk issues regarding eating and drinking. They discussed perceived inadequacies in SLT education, resulting in difficulties in MDT decision making at the end of life, when a nil by mouth order may be less patient centred (Stranberg et al, 2015).

Other suggestions about what is needed included the development of an online forum for learning and sharing experiences. The RCSLT does in fact already have an online forum 'the hub' (RCSLT.org) which provides a means forum for professional discussion, evidence sharing and debate.

The focus group discussed succession planning, in relation to avoiding early specialisation and ensuring that skills were maintained and developed in the future workforce.

Several participants suggested a need for further specific professional guidance. Perhaps a short module on such situations would greatly enhance the confidence of future clinicians. This should be considered by Higher Education institutions as the topic of end of life is likely to become a more significant area of allied health professions workload, with the increasingly ageing population (ONS, 2015). In addition,

a multi-disciplinary learning opportunity may also be of benefit as it would offer the opportunity for developing role awareness and discussion across professions.

Future Developments

Within stroke and elderly care, there have been increasing discussions about risk management. Hansjee (2013) examined seven complex cases regarding eating and drinking decision-making within elderly care. She highlighted delays in decision-making regarding nutritional needs. The author went on to develop a risk feeding protocol to facilitate more prompt decisions. Other initiatives such as the development of educational packages regarding maintaining oral intake in the face of recognised risks, have been proposed such as that of Sommerville et al (2016). This is a welcome addition and is highly relevant to the recommendations of this study as a step towards beginning to tackle this challenging area of practise.

Within the context of the case for seven day working in the NHS, Freemantle et al (2015) reported an increased risk of mortality for patients admitted to hospital during weekends. They suggested a need to identify which services need to be improved at weekends one of which might arguably be SLT. The authors suggested a need to ensure that patients needing end of life care receive the right treatment at the right time, regardless of when they are admitted to hospital (Freemantle et al, 2015). This is something which the SLT profession may need to consider.

Table 10 Summary of Recommendations

UNDER GRADUATE	POST GRADUATE	WORKPLACE /SERVICE ISSUES	PROFESSIONAL
TERMINOLOGY PC VS EOL	SLT FOCUS COURSES	PEER AND SENIOR SUPPORT, OBSERVATION, SHADOWING	
ETHICS	ETHICS	ACCESS	ROLE
CONCOMITANT ISSUES – BROADER PICTURE	LEGALITIES	SUCCESSION PLANNING	PROFILE
ROLE	EFFECTIVE MULTI-DISCIPLINARY COMMUNICATION	ATTENDANCE AT MDT MEETINGS	PRESENCE IN GUIDELINE DEVELOPMENT
PROCESS OF DYING STAGES	PAIN CONTROL	SUPERVISION	MDT WORKING
PATIENT CENTRED DECISION MAKING	MDT ROLES	PRESENCE	GUIDELINES
RISK MANAGEMENT MDT WORKING		SETTING	HOSPICE MODEL
SUPPORT	SUPPORT	APPROPRIATE REFERRAL	ONLINE LEARNING
SENSITIVE CONVERSATIONS	WHETHER TO WITHDRAW	MDT WORKING AND ROLE PROFILE	
EXAMPLES OF COMPLEX CARE			

Detailed Recommendations

The following section and table 10 on the previous page, outline the main recommendations of this research. Recommendations are presented in the order in which they arose rather than in any hierarchical format.

Under-graduate

The study recommends that all under-graduate SLTs, should be aware of relevant terminology related to end of life. The data suggested that there is currently wide variation in how terms such as 'end of life' and 'palliative' were interpreted by participants. Without a fundamental, shared understanding of such terms, it is difficult to see how SLTs can clearly evaluate their contribution and clinical decision-making.

In addition, training in ethical principles and particularly the practical application of ethics within healthcare would be of value in equipping SLTs with the necessary knowledge to formulate appropriate decisions.

Under-graduates should be given an understanding of complex cases including concomitant issues such as multiple pathologies, psycho-social factors and parallel treatments. Without such a broad understanding, SLTs may find it difficult to base their treatment decisions holistically.

A clearer understanding of the role of SLTs at this stage of care, should become part of the standard under-graduate education. According to the evidence found in this study, SLTs are currently unclear about their specific role and its boundaries and remit.

In addition, some exposure to the roles and remits of other members of the MDT should be included at under-graduate level. This could take the form of guest lecturers providing an overview along with links to relevant further resources.

This study indicates a need for under-graduate education to include some input regarding the nature of medical care and the dying process and what to expect. This might also include some overview of pharmacology and pain control, which were issues mentioned by the participants in this study.

Student SLTs should be able to explore the principles of patient centred care and patient led decision making. Some participants appeared to be unsure about whether to withdraw if a patient made a choice outside of the SLTs preferences. The opportunity to debate and discuss how best to manage such situations should be included within under-graduate education.

Although student SLTs will not face end of life issues unsupported, it is recommended that support systems be discussed with under-graduates, both in terms of support during training and later in the workplace. The topic of support was one that was introduced by the participants in this study and came to take a place of prominence in the overall findings. This would suggest that there is a need to consider these issues at all stages in the SLT career framework.

Some education regarding how to broach sensitive conversations would benefit under-graduate SLTs. Although, again they would not be doing this aspect of the role without supervision, the evidence from this study suggests that not all participants felt fully confident about undertaking this type of intervention.

Post-Graduate

This research, whilst demonstrating that many of the participants had attended a variety post-graduate training of varying degrees of relevance, did also suggest a need for some SLT specific input. Many of the participants described having learned via 'on the job' learning. As reported earlier, Ray et al (2014) in their consideration of multi-disciplinary palliative care education, reported that in considering all participating professions, those who had 'on the job' training alone had significantly less confidence in this area of work than those who had post-graduate qualifications. The findings of this research would support that finding, indicating a need for further educational resources which is beginning to be addressed.

There is a developing resource of learning materials related to multi-disciplinary education, such as the 'Palliative care in practice' website of NHS Education for Scotland (NES.scot.nhs.uk) and the 'Quality end of life for all' programme produced by

St Christopher's Hospice in London (www.stchristophers.org.uk). This is undoubtedly of great value, however, some aspects of the SLT role such as managing risk within eating and drinking recommendations, would seem to require to be addressed more specifically. This might be in the form of online learning or external courses, which should include a practical component and the opportunity for reflection and discussion.

Ethical issues within the workplace should also be a part of post-graduate training. Practicing SLTs should be comfortable with how ethical principles are addressed within the healthcare environment. Information regarding local ethics advisors and how to access resources would also be of benefit.

Knowledge of the legalities of end of life care should form part of post-graduate SLT education. This should include relevant issues such as capacity issues, patient centred choices, power of attorney and advanced directives.

In addition, some training regarding effective multi-disciplinary communication and decision making, would be of benefit in view of the comments about these issues.

It was demonstrated that some participants felt a lack of clarity regarding their role. This seemed to be linked to increased professional anxiety about whether to withdraw from cases when patients made decisions outside of the SLTs preferences. Some participants in this study were concerned about potential litigation in this respect, so a transparent discussion of such issues would help to clarify whether this was in fact a legitimate fear within the multi-disciplinary care environment.

Post-graduate SLTs would benefit from a clearer understanding of both the SLT and MDT roles and remits. A more detailed understanding of medical and multi-disciplinary management of end of life care would be of value. This should include specific aspects of relevance to the head and neck cancer population, which might include an overview of radiotherapy, chemotherapy, pain control and pharmacology. It should also include discussion of how a changing clinical picture is identified and addressed. Finally, as with under-graduate recommendations, support systems for post-graduate SLTs should be given full consideration within any SLT specific training.

Workplace/Service issues

As with the previous sections on under-graduate and post-graduate recommendations, support systems need to be fully integrated into service planning. This research demonstrated considerable emotional impact on participants. In order to maintain a healthy and effective workforce, support systems should be incorporated into service planning at all stages of workforce development. This should include peer support, observation/shadowing, senior support, supervision and external support systems.

Service providers should consider how easily and by whom their service can be accessed. A more transparent and consistent approach would facilitate equity of service provision. A detailed examination of referral sources, referral pathways and potential barriers should be undertaken. It is recommended that this includes seeking the opinions of other members of the MDT, as well as engaging the views of patients and carers.

Since succession planning was raised as an issue within the focus group, it is suggested that SLT service planners review how future workforce needs are being addressed. There would be great benefit in facilitating less experienced SLTs to enter this field, within an appropriately supportive service structure. The fact that some participants discussed a 'fear' to enter this field suggests a need to review current service models.

In view of the comments regarding poor awareness of the SLT contribution amongst the MDT, it would seem sensible to suggest that service planning addresses these issues. This might involve building in provision to allow attendance at relevant team meetings and increased, visible presence within the MDT. Increased presence and participation may also address the reported difficulties with appropriate referrals. Increased communication and interaction amongst the team would enhance shared learning opportunities in both directions.

The setting in which care is delivered, also requires consideration by service planners. The participants in this study described their perception of differences in how care was delivered across settings. There was some suggestion that clinical decisions were influenced by the setting, with more risk averse decisions being made on busy acute

wards. If this was found to be a widely held view, this would require to be addressed as it might indicate some potential inequity.

Professional

In terms of recommendations for the SLT profession, the evidence from this study indicates a need to develop an agreed role outline. It would seem that the participants were seeking further clarity about their specific remit and professional boundaries. It is suggested, therefore, that some specific guidelines about the role of SLT in end of life care and in particular within HNC are indicated. The forthcoming online clinical resources (RCSLT, 2016), may serve to address this need.

A further finding was the perception of some participants, that the SLT profession needed to increase its profile within HNC end of life care. The lack of SLT inclusion in some recent guidelines would suggest that there is indeed still some work to be done to ensure that SLTs are viewed as core members of the multi-disciplinary team. It is recommended that the SLT profession pro-actively engages with consultations regarding end of life and HNC, in order to take up the opportunity to raise professional profile within the wider healthcare community.

The SLT profession may wish to consider exploring differing models of care delivery such as the hospice model, both with a view to extending SLT input to these areas, as well as considering how hospice principles of care might be applied within other settings. Some participants in this study expressed a view that care was more effective within the hospice environment, this is certainly worth examining more closely to establish how valid this view might be.

Reflections on the research process

General reflections on the research process are included in the appendix (pp 197)

Design

The research design was selected following a review of methodologies and some time was spent considering which of these would answer the research question most appropriately. Although a number of different qualitative, quantitative and mixed methods approaches could have been utilised, the author identified most, with a qualitative and phenomenological approach. This aligned most closely with the author's views on how to gain the richest, most revealing data, whilst acknowledging the researchers place within the findings. Although this method proved extremely time consuming, the resultant findings proved to be of the depth and richness which had been aspired to at the outset.

The theoretical framework chosen for this study provided a useful structure with which to consider the differing levels of influence on individuals. Considering the participants as parts of a complex ecological system, seemed fitting in that it allowed for differing levels of analysis and spheres of influence to be approached in a logical format. Without this structure, it may have been difficult to explore the inter-relationships in a coherent manner.

Limitations

Due to the qualitative nature of the design, participant numbers were low. The research focussed on the NHS in Scotland, so the results may not be transferable to NHS services in the rest of the UK. Also eight of the final eleven participants were from the same Scottish Health Board, although some attempt was made to gain representation from a wider group by including three other participants from neighbouring Health Boards. It is possible that the majority of participants being from a single Health Board may have impacted on the findings to some extent, which should be borne in mind when evaluating the utility of the study. The responses of the eight participants from a single Health Board, may also have been affected by the reported organisational

change which took place during the time of this research. This should be borne in mind when interpreting the outcomes, although on reflection, the participant's reports appear in the most part, to relate to longstanding issues.

An additional potentially limiting factor is the researcher's professional role as Team lead for six of the participants. It is possible that this may have in some way inhibited some of the material offered by participants, in view of the existing supervisory relationship. In examining the data however, this would seem to be less of an issue, since most participants discussed a number of service provision related issues within the interviews.

It should be noted that had the choice been made to approach this investigation from the viewpoint of a service commissioner, its conclusions may have been rather different. It is possible that through this lens, the SLT professional contribution may have been viewed as less robust. It is possible that from this viewpoint, it might have been considered that SLT involvement is not of benefit and in fact delays discharges and impacts on quality of life and team decision making. Had this view been taken however, it would have missed the vital contribution that the SLT makes in raising complex, ethical dilemmas and enabling the patient's voice to be heard.

Credibility

The depth of analysis and transparent methods of data handling, make this a credible piece of research in the context of the participants interviewed. The specific approach taken ensured constant review and error checking during the course of the research. This has produced data that is robust within the context of the study.

Whether this data represents a wider picture is unclear but it provides an in depth baseline for future researchers to further explore this area.

Why is this research relevant now?

The level of media interest in issues related to end of life care has been prominent throughout the course of the study and indeed has increased with recent reports of an audit by the Royal College of Physicians (BBC news 2/5/16) indicating a failure of NHS staff to discuss 'do not resuscitate' orders in one out of five cases. Whilst this is not directly related to eating and drinking, a parallel could be suggested in terms of staff making decisions regarding oral intake without the full knowledge of the patient and family regarding the potential implications of making that decision (whether that be a decision to continue or to cease oral intake). There is a sense that overall, more needs to be done to improve communication with patients and carers and across the MDT, in order to achieve a truly patient led service at this vital stage of life.

Summary

This project has answered the research question and demonstrated a clear learning need for the profession of Speech and Language Therapy which if addressed, would enhance patient experience and professional development within an ageing population. The project could readily be applied to a number of related professional groups, who historically have not received training in palliative care approaches. The final chapter will consider the conclusions of the research in terms of meeting its overall aim, contribution, utility, recommendations and limitations.

6 Conclusions

Aim

The main aim of the study was to demonstrate what practising SLTs reported as key issues in delivering end of life swallowing care to adults with head and neck cancer. Additionally, the study aimed to provide a basis for supporting the development of future SLT education by identifying SLTs experiences of preparation for this role. The final aim of the study, was to contribute to the SLT profession's ability to meet the needs of SLTs by identifying what they thought was required to provide this care effectively.

Original Contribution

In terms of contribution of knowledge, the literature revealed a need for further research into the SLT role in end of life care for people with head and neck cancer. The professional body of SLTs, the RCSLT, had also recommended further research into the SLT role in end of life care within their clinical guidelines. However, little information was available regarding how SLTs experienced this area of clinical work. This study has provided an in depth account of the experiences of SLTs from four different Health Boards in Scotland. Although the numbers were small, it is hoped that this study can pave the way for further exploration of this topic, by providing some initial insight into the experiences and needs of practicing SLTs with a view to informing future professional and service planning. The study has revealed specific issues with regard to role clarity, emotional impact and team communication. The issue of emotional impact in particular, has not been discussed in depth in the existing literature to date and this study begins to address this need.

Utility/application of this knowledge

This study informs Professional practice by providing an insight into the stated needs of SLTs in terms of professional guidance, support and development. It is hoped that this study can begin to contribute to the development of future SLT training and service provision. An initial dissemination record and strategy has been prepared. (Appendix pp 226)

This project has the potential to have an impact on the Speech and Language Therapy profession in terms of education, clinical guidance, multi-disciplinary working and patient led decision-making approaches. The project is transferable with minimal modification and the conclusions of the project suggest a potential for wider application across the Allied Health Professional group, where to date, exploration of staff experiences and education in palliative care remains limited.

The study suggested that there were unmet needs for SLTs with regard to preparation and training which aligns with the reported findings of O'Reilly and Walsh (2015), who conducted an international online survey of the role of Speech and Language Therapists in palliative care. They concluded that the role was under-resourced and suggested a need for further research and specialist training.

A significant finding of this research was the reported emotional impact of this area of practice on SLT clinicians. Kelly et al (2016) commented on issues around the potential impact on SLTs of working with people who were dying, which resonates with the findings of this study.

The findings of this research also suggested a need for further guidance for SLTs, which seems to support recent publications including Chahda et al (2016) and Kelly et al (2016). Both of these authors conducted literature reviews concerning the role of SLTs in palliative care and suggested a current lack of research on this topic and a need for further guidelines for SLTs working in palliative care. Lawson et al (2015), in a preliminary examination of the international literature regarding dysphagia therapy in HNC, (in order to develop Australian guidelines), noted a lack of evidence on this topic.

An additional significant finding, was the number of comments regarding multi-disciplinary communication. Whilst there were many positives, the data also revealed a number of challenging aspects experienced by the participants. Cocks et al (2016) in a publication outlining new UK national multi-disciplinary guidelines on HNC, included the recommendation for regular multi-professional assessment for dying patients in order to monitor and revise care plans.

Recommendations

The study makes a number of recommendations including:

The need to consider future requirements of under-graduate, post-graduate and workplace learning opportunities for SLTs in the context of end of life dysphagia care for people with head and neck cancer.

The need to ensure wider access of available guidance documents and the development of more profession specific guidance to practicing SLTs.

A role for the profession in raising presence, visibility and role profile within this area.

A further role for the profession in ensuring that service commissioners are aware of the contribution of SLTs in end of life care.

Final Comments

In summary, this research set out to explore the lived experience of SLTs in working with people with HNC with dysphagia at the end of life. The research revealed a considerable emotional impact across all participants, along with multi-disciplinary communication challenges and a clear sense of a lack of preparation for this sensitive and complex field. This needs to be addressed as a priority in order to improve safe, patient centred care and staff wellbeing.

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Personal Motivation

Having worked in the UK NHS for a number of years across a range of caseloads as a Speech and Language Therapist, specialising in head and neck cancer care, I perceived a lack of confidence amongst the SLT profession in relation to what SLTs should be doing with people during this phase of care. Over the years after many discussions and sometimes a multitude of opinions within the multi-disciplinary team around what was the best approach for specific cases, I came to the conclusion that more information was needed in order to clarify the position for future SLT staff. A longstanding role as an advisor for RCSLT also indicated some uncertainty amongst SLTs with regard to managing end of life dysphagia care for people with head and neck cancer. A lack of confidence and anxiety about decision-making around risks was anecdotally observed.

Arguably, there can be few more important aspects of care than supporting someone who is nearing the end of life. Professionals should be able to discuss issues around this aspect of care openly and transparently. It would seem logical to suggest that staff need to have the skills to contribute positively to the experience for the individual concerned whilst also managing any personal impact effectively.

During my career I have observed a multitude of healthcare initiatives and re-organisations, often politically driven which sought to improve healthcare. Often, new measures thought to improve services appear to have resulted in more confusion and less time to consider the issues that really matter. Humanity and compassion appear to have been forced into a back seat position behind targets and financial constraints. This may sound like a tired argument and it is certainly true that efficiency initiatives have in some cases resulted in considerable improvements in patient care. However, for the most part, when something has to give it has often appeared to be the 'soft' difficult to measure aspects of care such as end of life care that have had to bear the brunt by moving out of the central focus of attention.

Unfortunately, for many years, I observed this situation and witnessed end of life care in acute settings that was far from ideal despite the best efforts of those involved.

Completion of the RCSLT Advanced Dysphagia qualification in head and neck surgery led me to undertake an initial exploration of end of life dysphagia care in terms of decision making. A number of years later, SLT end of life dysphagia care in head and neck cancer remains an area which has not yet been fully explored or clarified. This leaves practising clinicians in need of further information and guidance as to how they should approach delivering this type of service.

Teaching for a number of years on a university graduate nurse programme in head and neck cancer, informally revealed variable anecdotal accounts of SLT contribution and inclusion at this stage of care, indicating some inconsistency in the type and extent of service involvement across clinical settings.

The ongoing RCSLT 'Giving Voice' campaign seeks to raise the profile of the value that SLT input can bring across a range of conditions in the current context of service pressures and threats within the NHS (RCSLT 2016). The role of SLTs in palliative and end of life care is an example of an area of practice that is still at a relatively early stage of development and would benefit from further examination.

More recent influences on the motivation for conducting this study include the researcher's involvement in the NHS Education for Scotland SLT 'Think tank' (later re-named 'Advisory Group') which had a remit to consider learning and education needs for the profession (NES 2013). The author's current contribution to the forthcoming RCSLT review of Curriculum Guidelines (RCSLT, 2016) also provides a forum for discussion of current professional issues and developments.

Typically, in the acute setting, swallowing difficulty (i.e. dysphagia) is managed by Speech and Language Therapists with the overall aim of trying to prevent the occurrence of aspiration of food and drink into the airways and the ensuing risks associated with such events, such as the development of an aspiration related pneumonia which can prove fatal. This management typically involves either withdrawing oral intake or modifying the textures of food and drink given to people at risk of experiencing such difficulties. Differing strategies may also be suggested such as altering the rate of intake, placing of the bolus in different areas of the mouth,

modifying the type of cup used for fluids (e.g. using a 'bolus control' mug which only allows a certain quantity per sip) or postural advice to facilitate more effective clearance (e.g. tucking the chin to aid airway protection). SLTs attempt to assess and advise on the safest option.

Example Phrases and line numbers from Pilot 1

Acute setting (75)
HNC relatively new for me (75 -77)
Cover the wards (79)
Trained in laryngectomy valve work which is very exciting (82/84)
Independent in changing valves (87-89)
Great I thoroughly enjoy it (95)
What I ultimately wanted to do when I came into SLT (95-97)
Really pleased to gain lots of experience (97-100)
Learned a lot in a very short space of time (99-100)
Doing it for ten months (102)
Learned an awful lot (104)
I thoroughly enjoy it (107)
Most of the work with dysphagia (115-116)
MSAS carried over into HNC (118-119)
Style of dysphagia management is different (130-137)
Cognitively intact, mobile younger (139-145)
They're making decisions (144)
Maybe they're a lot younger (144-145)
Different style of management (148-149+)
Not gung ho but (149-151)
Make the decision with the patient and the MDT and everybody (152-155)
Patients have a large role (155-152)
Patients undergoing radiotherapy (163-165)
Clearly very unsafe with anything (167)
Continue to try and use your swallow (173-174)
So...things keep on moving (176-177)
Trying different postures manoeuvres etc (177-180)
Good oral hygiene (183-184)
Patient aware of aspiration risk (186-188)
Safest thing to aspirate (188-189)
Good oral hygiene (190)
Still a risk (192)
Different style of dysphagia management (193-195)
Piecing together a huge puzzle (197-198)
Knowledge of anatomy (199-201)
Knowledge of effects of treatment (200-203)
Bring it all together (206)
More proactive, doing things to maintain (207-210)
Quality of life (214)
Limited experience of eol (223-224)
More complex patients (227-228)
More experienced therapists worked with these patients (231-234)
Work with patient and family (237-239)
Maintain their QOL (241-242)
Trying a wee bit of something when it's quite risky (243-246)
This is what might happen (247-248)

These are your options (250-251)
 Risks and benefits (253-255)
 Quality of life (257-259)
 Younger patients (261)
 Helping them to manage (268-270)
 Families (272)
 Swings and roundabouts (287-288)
 Counselling (294)
 So many questions (299-300)
 Specific role (300-301)
 The more I do the more I learn about MDT roles (302-303)
 Help them understand (301-307)
 Working with all the staff (309-310)
 More of a role within MDT (than in acute) (310-313)
 Slightly different (re MDT working in HNC)(315)
 On the same wards (316-318)
 Everybody knows who you are (318-319)
 Really part of the team (319)
 More places to cover (321-323)
 Laryngectomy patient passed away (352)
 Really sad (356)
 Really lovely patient (357)
 Everyone was so sad (357-358)
 Patients... can be around for years (HNC) (361-363)
 They come back (365)
 Things extend, radiotherapy, more problems (367-371)
 Very sad for everybody (373-376)
 Team had a positive role (376-378)
 Counselling (378-381)
 Patient realisation - palliative (381-384)
 There was nothing they could do (386)
 The family were very very angry (387-388)
 Family felt we were here to listen (390-391)
 Other people don't have time to listen (391-392)
 Maybe we have a bit more time (397-398)
 Quite nice 'cause you get to know people (407-408)
 Quite nice, get to know them (412-415)
 Get to know their history (415)
 Get to know their family (416)
 Continually supporting for the long run (420-421)
 Helping them to realise (430)
 Quite nice in a selfish way (436-437)
 Aiding (MDT/Patient/family) (449-451)
 Assessing their safety (451-453)
 Advising (454)
 Role in flagging up (to professionals/patients) (460-462)
 Don't have to follow what we say (462-464)
 It's their choice (464)

Advice and guidance (464-465)
 Give them information to make an informed decision (466-468)
 Giving them information (468-470)
 A wee bit of power (470-471)
 To make a decision themselves (470-472)
 Guide them (473)
 Review (473-474)
 Want to try eating and drinking (475-477)
 Don't want to adhere (477-478)
 A role further on (481-483)
 Not purely assess and discharge (483-484)
 Management (485)
 Emotional aspect (patient) (495-497)
 Young (498)
 Young (500)
 Quality of life (502)
 Guidance and advice (505)
 What they want to do with the information (507-508)
 Emotional aspects (patient/families) (512-514)
 Complex (521)
 Really affected those people (staff) (523)
 Presentation/speed/physical changes (524-527)
 Staff asking advice (529-532)
 Everybody's been affected (534)
 Empathy is such a big thing (535-537)
 Put yourself in the patient position (538-539)
 How you would feel (539-540)
 How you would like to be treated (540-541)
 Patient centred management (543)
 Just looking for answers and someone to fix (patients) (551-553)
 Many times you don't fix the problem (553-554)
 They're wanting us to come along and fix it (555-557)
 Role isn't well understood (557-558)
 Portrayed that we can fix things (560-563)
 Advice and guidance (571-573)
 Therap them into becoming better (575-577)
 Role – assess safety and offer advice (581-584)
 Guidance (586-587)
 I never say I can fix the problem (591-592)
 I can't fix (594-596)
 Study day for people new to HNC (604-610)
 Small group (626-627)
 Opportunity to ask any Qs we wanted (for SLT) (627-629)
 I learned a lot there (636)
 Learning on the job is one thing..able to sit down/asking things (638-643)
 How much information to give (645-647)
 It was do this do this (re training course)(649-650)
 Supportive role (re training course) (651-652)

This is your role (re training course) (654-655)
You are not here to fix it (655-656)
This is your small portion of it (657)
I feel very supported by senior colleagues (660-661)
Much more experience (663-664)
More confident (671-672)
Tiny role (672-675)
It's a really important one (re role) (674)
You need this as well as all the other bits that's why it's an MDT (674-679)
Make me feel confident (re training course)(681-683)
Asking things (re training course) (685)
Patients can ask us Qs all the time (685-687)
We don't feel we can answer (689)
How much information to give (689-692)
Medics should have answered that Q (693-695)
A bit more confident (697)
Valve training (713)
Shadowing (717-718)
Attended a course on VF (720-723)
Found it really useful (728-729)
Specialist in HNC..this is what the anatomy can look like..(re training course) (731-734)
Management is different (re training course)(736-737)
Try manoeuvres, there might be aspiration..then try something else (re training course) (739-741)
Slightly more aggressive in your management (re training course) (743-745)
Push the patient as far as you could (re training course) (745-747)
See..what benefits you could get (re training course) (747-750)
It's ok... to try things and see (re training course) (770-771)
...the first two ...don't work but the third or fourth one might (773-777)
Limited time in the clinic (778-781)
You should be trying all these things (782)
Patients...willing to try (783-785)
Work with you and see what they can achieve (787-792)
Recapping on anatomy/tumour sites/surgery (793-797)
Learned a lot (800)
Very brief placement/rotation (811-813)
Under-graduate training...really very very minimal...written work (815-817)
Placement (819-832)
Before I went there I felt like I knew nothing (827-828)
Three week block...my knowledge had just soared (833-835)
That was the only thing I was offered at under-graduate (837-840)
I don't remember any lectures specifically on HNC (848-853)
Nothing specific to this (re under-grad training) (855-856)
Rehabilitation...getting someone back...as good as they can be (866-869)
Ability to move forward (869-870)
Gain something from the work you're putting in (870-872)
Palliative care..unlikely to make a lot of gains (874-875)
Limited forward movement (876-877)

Won't be any rehabilitation per se (877-878)
 Role in maintaining (878-880)
 End of life..comfortable as possible (882-884)
 You're not rehabbing them (884-885)
 You're not hoping to make big gains in moving forward (886-887)
 Keep them as functional as possible (887-888)
 As comfortable as possible (889)
 Why do we need you (Re SLT) (900-904)
 Just let them eat and drink whatever they want because they're end of life (902-906)
 I've had to learn to stand my ground...but we can offer advice and guidance (906-909)
 To make people more comfortable (909-910)
 Help the nursing staff...aiding somebody...clearly aspirating (911-915)
 It can be very uncomfortable for the nursing staff (916-917)
 ...offering guidance (918)
 ...people aren't as aware of our role (918-920)
 ...enough therapists (937-938)
 ...spend time with your patients (938)
 They need time, they need to ask all the Qs (938-941)
 See them regularly (943-944)
 Make sure that they are comfortable/happy/not distressed (946-948)
 access to VF (949)
 You're not making assumptions (re use of VF) (952-955)
 A clear picture (955-956)
 Working within a good MDT (956-958)
 Aware of our role (958-959)
 We know what their roles are (re MDT) (959-960)
 We know what the crossovers are (961-962)
 More time with them (970-971)
 There's a lot of other stuff to do as opposed to just see patients (973-977)
 Time to spend with patients (992-993)
 To do what we should be doing (993-994)
 It needs to be fairly specialist (997-999)
 Our understanding of how disease progresses (1000-1001)
 Structures that are affected (1002-1003)
 General HNC management (1003-1004)
 Need to be quite specialist (1004-1006)
 A lot of people are very very frightened of doing it and would hate to do it...you hear that from people (re SLTs) (1006-1010)
 You hear people saying I don't know how you could do that (re SLTs) (1012-1013)
 ...it's a bit scary but I think maybe just time (1015-1016)
 ...don't remember covering that at university (1029-1030)
 ...because we did the course in two years as opposed to four you just had to learn it Yourself (1032-1035)
 Very different if you do an undergrad course (1038-1039)
 ...totally specific to what university you go to (1039-1040)
 ...their own teaching style (1042-1043)
 ..probably quite unusual for the place that I went (1044-1045)

Pilot 1 analysis Grouped Data

Emotional impact

on SLT

Really make a difference
Offer them a wee bit of comfort
Take something positive out of it
Positive work
Positive role
It feels like you're helping slightly
Helping them makes you feel good
Can't offer anything
You can't do this you can't do that
Now you can't eat or drink
It can be quite difficult
Can't fix them
(You) pile on top of this pile of negativity
When we can't fix things
Not able to fix
Many times you don't fix the problem
I can't fix
Patient death
Really sad
Really lovely patient
Empathy is such a big thing
Put yourself in the patient position
How you would feel
How you would like to be treated

On team

Everyone was so sad
Really affected those people (staff)
Everybody's been affected
Very sad for everybody
Team had a positive role
It can be very uncomfortable for the nursing staff (feeding when aspirating)

on patient

Patient realisation
There was nothing they could do
emotional aspect (patient)

on family/carer

The family were very very angry
Family felt we were here to listen
Other people don't have time to listen
Maybe we have a bit more time
Emotional aspects (patient/families)

Clinical

Presentation/speed/physical changes

QOL

Quality of life
Maintain their QOL
Quality of life
Quality of life

Type of patient

Younger
Maybe they're a lot younger
Younger patients
Young
Young

Cognitively intact

Around for a long time

Patients... can be around for years
They come back
Things extend, radiotherapy, more problems
Continually supporting for the long run

Get to know them well
Quite nice 'cause you get to know people
Quite nice, get to know them
Get to know their history
Get to know their family

Mobile
Younger
More complex patients
Complex
Patients undergoing radiotherapy

Style of DG management is different in HNC

Style of dysphagia management is different
Different style of management
Not gung ho but..
Different style of dysphagia management
More proactive, doing things to maintain
Slightly different
Management is different (re VF course)
Try maneuvers, there might be aspiration..then try something else
the first two ...don't work but the third or fourth one might
Slightly more aggressive in your management
Push the patient as far as you could
See..what benefits you could get
My experience has taught me - Its ok... to try things and see
Limited time in the clinic
You should be trying all these things
Patients...willing to try
Work with you and see what they can achieve
Recapping on anatomy/tumour sites/surgery
Learned a lot

Definitions

Rehabilitation
Rehabilitation...getting someone back...as good as they can be
Ability to move forward
Gain something from the work you're putting in

Palliative care
Palliative care..unlikely to make a lot of gains
Won't be any rehabilitation per se
Limited forward movement

End of life
Role in maintaining
comfortable as possible
As comfortable as possible
You're not rehabbing them
You're not hoping to make big gains in moving forward
Keep them as functional as possible

Preparation

How much to say
No lectures
Very brief placement/rotation
Placement

Before I went there I felt like I knew nothing
Three week block...my knowledge had just soared
That was the only thing I was offered at under-graduate
Under-graduate training...really very very minimal...written work
I don't remember any lectures specifically on HNC
Nothing specific to this (HNC)
End of life
...don't remember covering that at university
...because we did the course in two years as opposed to four you just had to learn it
Yourself
Very different if you do an undergrad course
..probably quite unusual for the place that I went
...totally specific to what university you go to
...their own teaching style

Sit down learning
Learning on the job is one thing..able to sit down/asking things

Confidence
Comfortable in knowledge of anatomy
Really pleased to gain lots of experience
Learned a lot in a very short space of time
Learned an awful lot
MSAS carried over into HNC
Study day for people new to HNC
Small group
Opportunity to ask any Qs we wanted
Asking things
I learned a lot there
More confident
Make me feel confident (re training course)
A bit more confident
It was do this do this (re training course)
Supportive role
This is your role
You are not here to fix it
This is your small portion of it
Attended a course on VF
Found it really useful
Specialist in HNC..this is what the anatomy can look like

Workplace learning
I feel very supported by senior colleagues
with much more experience
Valve training
Shadowing

Fear of the area of work

A lot of people are very very frightened of doing it and would hate to do it...you hear that from people

You hear people saying I don't know how you could do that
...it's a bit scary but I think maybe just time

HNC setting

Acute

On the same wards

Everybody knows who you are

Really part of the team

Non HNC acute settings

More places to cover

Level of experience

0-5yrs

Experience of HNC

Thoroughly enjoy it

What I ultimately wanted to do when I came into SLT

I thoroughly enjoy it

Experience of end of life

Limited experience of eol

Swings and roundabouts

Type of work

Most of the work with dysphagia

Risk management

Aware of risk

Patient aware of aspiration risk

Continuing to swallow when unsafe

So...things keep on moving

Clearly very unsafe with anything

Continue to try and use your swallow

Trying a wee bit of something when it's quite risky

Want to try eating and drinking

Don't want to adhere

A role further on

This is what might happen
Risks and benefits
Minimise risk
Still a risk
Maintain them
Safest thing to aspirate

Therapeutic strategies

Trying different postures manoeuvres etc
Good oral hygiene
Good oral hygiene
Review
Piecing together a huge puzzle
Bring it all together
Not purely assess and discharge
Management

Therapeutic skills

Knowledge of anatomy
Knowledge of effects of treatment
More experienced therapists
Specific role
It needs to be fairly specialist
Need to be quite specialist
Assessing their safety
Assess safety and offer advice

Joint decision making
with patient
They're making decisions
Patients have a large role
These are your options
It's their choice
With MDT
Make the decision with the patient and the MDT and everybody
The more I do the more I learn about MDT roles
Working with all the staff
More of a role within MDT (than in acute)
With carer
Work with patient and family
Families

Dealing with Patients
So many questions
Don't have to follow what we say

Role

SLT view

I never say I can fix the problem

Helping them to manage

Aiding (MDT/Patient/family)

Role in flagging up (to professionals/patients)

Advising

Advice and guidance

Guidance and advice

Advice and guidance

Guide them

Guidance

Offering guidance (to nurses)

Tiny role

It's a really important one

You need this as well as all the other bits that's why it's an MDT

Patient

Patient centred management

Help them understand

Give them information to make an informed decision

A wee bit of power

to make a decision themselves

Giving them information

What they want to do with the information

How much information to give

How much information to give

Counselling role

Helping them to understand

Counselling

Counselling

Helping them to realise

Knowledge of our role

Staff

Staff asking advice

Role isn't well understood

Why do we need you

Just let them eat and drink whatever they want because they're end of life

I've had to learn to stand my ground...but we can offer advice and guidance

To make people more comfortable

Help the nursing staff (who are)..aiding somebody...clearly aspirating

People aren't as aware of our role

Portrayed that we can fix things

Therap them into becoming better

What is needed

Staffing

Time to listen

More time with them

There's a lot of other stuff to do as opposed to just see patients

...enough therapists

Spend time with your patients

Make sure that they are comfortable/happy/not distressed

Time to spend with patients

To do what we should be doing

Access to VF

(So) you're not making assumptions (re use of VF)

A clear picture

MDT

Working within a good MDT

Aware of our role

We know what their roles are

We know what the crossovers are

SLT

Our understanding of how disease progresses

Structures that are affected

General HNC management

What the patient wants

Just looking for answers and someone to fix (patients)

They're wanting us to come along and fix it

Patients can ask us Qs all the time

We don't feel we can answer

Medics should have answered that

They need time, they need to ask all the Qs

See them regularly

Transcription Reflections

The researcher noted the impact of previous training in linguistics and phonetics which had to be set aside, in order to avoid making the process overly complex. This was initially viewed by the researcher negatively, in the perception that text alone without any notation of intonation or speech stress, may result in a misrepresentation of the participants meaning. However, it was clear that such a detailed transcript would be unwieldy and would require significant additional time to prepare, so this limitation was accepted and the simple template utilised. In addition, doing so, would risk unintentionally incorporating the researcher's own interpretation of the data. Instead, research notes were employed after each interview to provide additional context, along with ensuring that the original recordings were listened to regularly throughout the process.

Transcription was time consuming. Half of the initial pilot transcript took two days, in spite of being a shorter interview. Although some interviews were later transcribed more rapidly, in general they all took at least eight hours to prepare. This was in part due to the researcher's inexperience but was also due to a desire to ensure accuracy. Some participants spoke quickly or quietly and often at low volume, when discussing sensitive topics. This meant a lot of re-listening to ensure that the transcript was as accurate a record as possible of events. Although time consuming, re-listening resulted in enhanced familiarity with the data, which was ultimately considered beneficial.

The focus group was problematic in that one participant played a dominant speaking role, so the researcher needed to facilitate participation from less forthcoming members. Additionally, there were numerous inaudible sections where participants spoke together which resulted in some loss of data, as it was not possible to hear what all participants were saying even on repeat listening.

In reflecting on the process, it was clear that when transcribing, there was a need to avoid anticipating what might be said, with the result of altering the participants

meaning. It was essential to monitor carefully, to ensure that this did not occur. As a result, transcriptions were typed in short periods of time with breaks to avoid a loss of concentration. A further observation was that the researcher noted that some utterances recorded as inaudible, became clearer after moving on when listening for something else. When this occurred, it had to be re-checked to ensure that it was not an error. During the process, it also became apparent that the researcher's inexperience was evident in the form of some obvious prompts rather than probes and more researcher responses to participants commenting on areas of interest to the researcher. Once this had been noted in the earlier interviews, attempts were made to limit researcher responses in subsequent interviews.

On completion of the transcription process, all recordings were again listened to, in order to error check. General comments on the transcripts were prepared (Appendix pp 271). The researcher was careful to avoid including any utterances which were not absolutely clear. Finally, the transcripts were then printed out and sent to all pilot and main participants along with a copy of their original consent form and a request letter for them to contact the researcher with any alterations or amendments. No replies were received by the given response deadline. It was therefore taken that participants were in agreement with the transcript accuracy.

Recognition of a potentially negative impact of seeing the final transcript was noted particularly for those participants who had been very non-fluent i.e. hesitant or exhibiting 'false starts' or repetitions. This may have highlighted their communication style to them, which may not have been a positive experience. In an attempt to mitigate this, these transcripts were sent out with an explanatory note regarding the need for the researcher to record all utterances on the part of both the researcher and participants and that this was part of the transcription process. Recording in this detail however, proved useful in the analysis phase, as in some cases, hesitations and false starts were noted to occur when discussing more sensitive topics which is discussed further in the findings chapter.

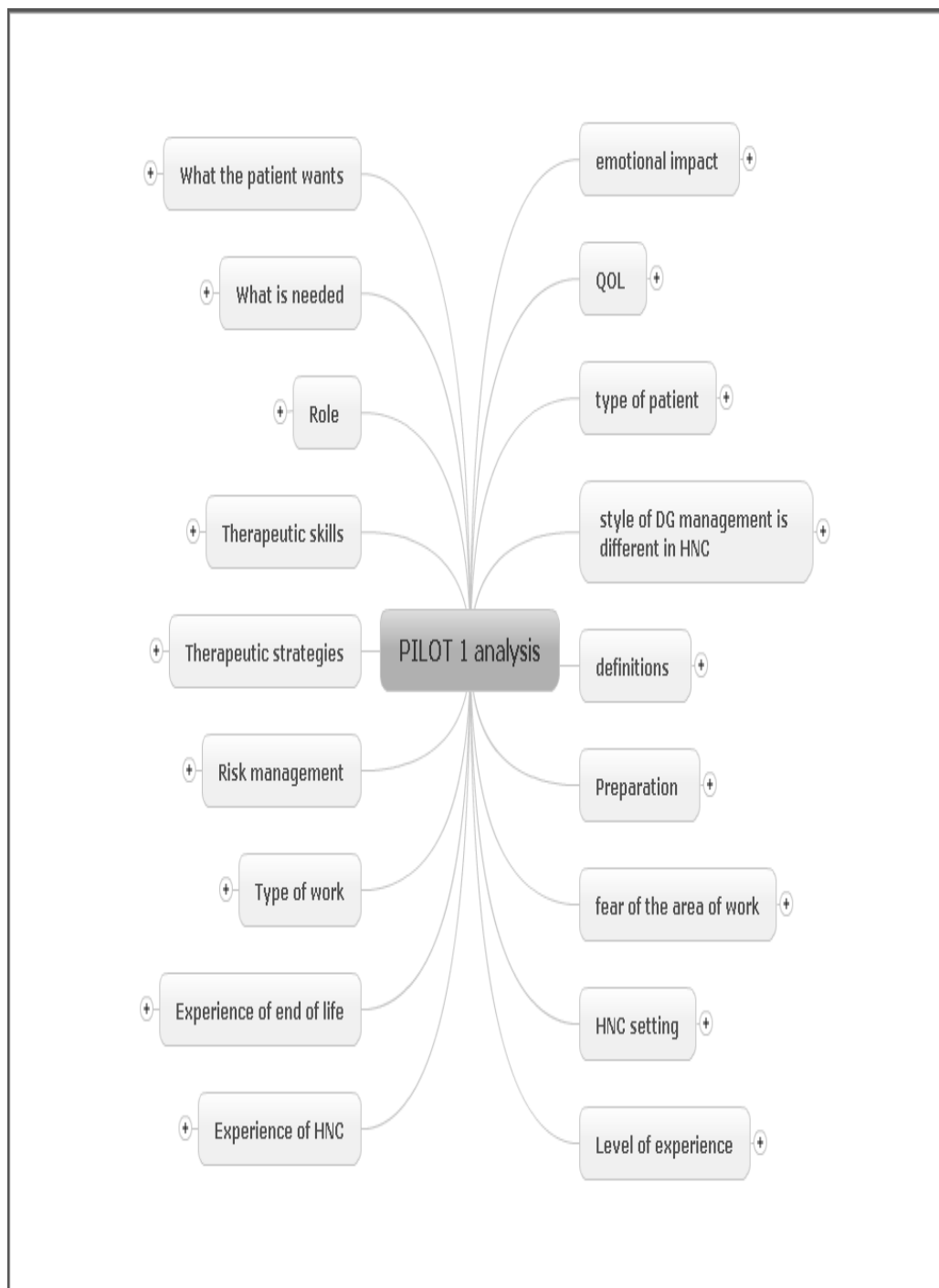


Figure 3 Screen Shot of Pilot 1 analysis using Mindmanager software to create mind map – shown 'closed' with individual transcript main themes visible.

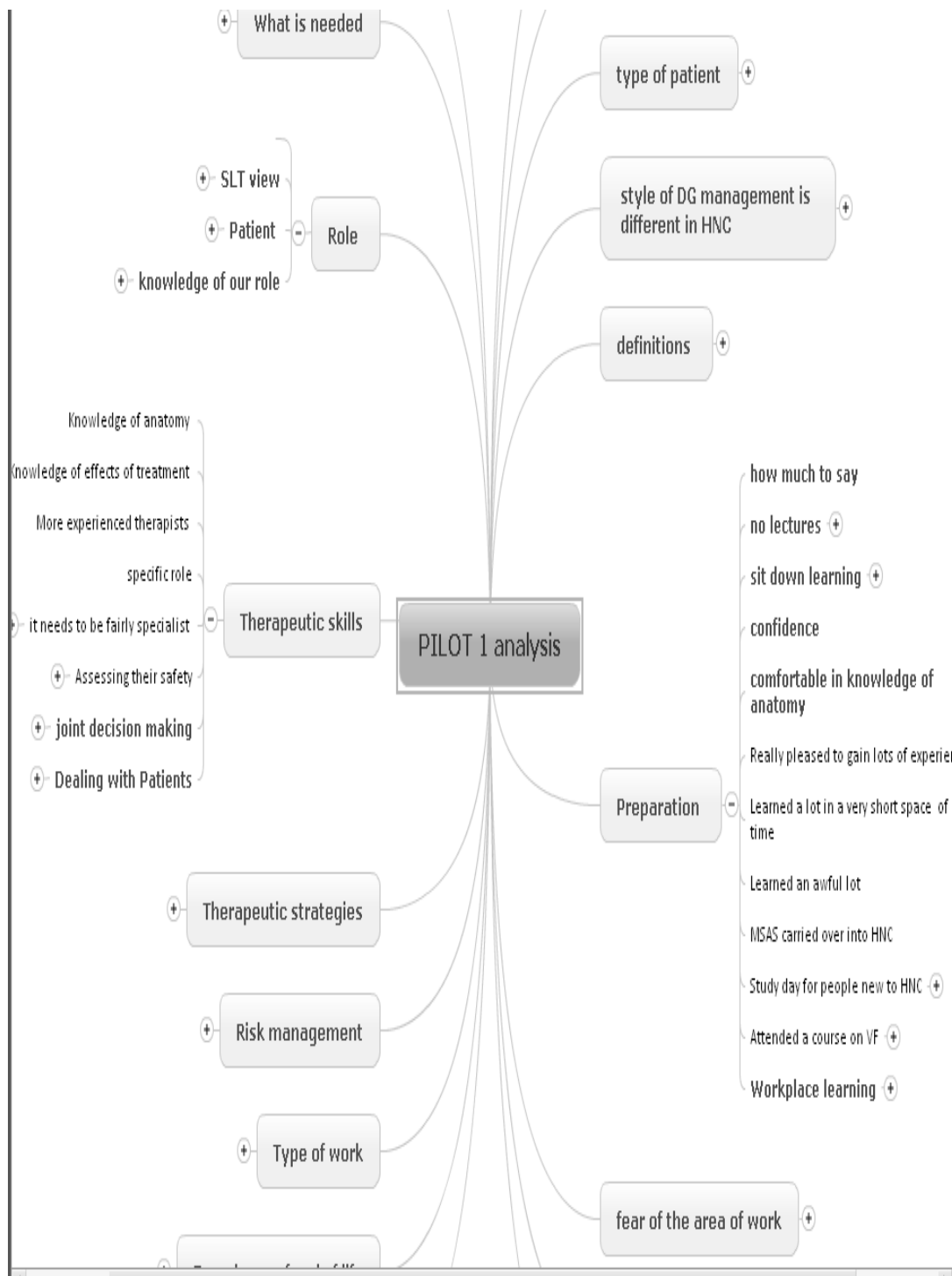


Fig 4: Screen shot of Pilot 1 analysis using Mindmanager software to create mind map – shown with some nodes opened, ‘+’ denotes further linked nodes leading towards groupings and original data excerpts

General reflections on the research process

The study resulted in an enthusiastic response from participants who appeared keen to take up the opportunity to discuss their experiences and did so with great trust and openness. Some of the anecdotes shared were very moving and seemed to demonstrate a considerable impact of this area of work on participants.

Several commented outside the interviews, that a study such as this was much needed and that they hoped it would lead to improvements in their working lives and in the care of their patients. As a result, it was essential to approach the study with a sense of great responsibility. It was vital to ensure, having been entrusted with the openness, honesty and hope of participants in sharing their personal experiences, that the topic was approached with care and that the findings were carefully considered. This was quite a daunting prospect in terms of the resultant responsibility it placed on the novice researcher. Having devised the interview prompts based on the findings of the initial literature search, the most common topics had been included however, it rapidly became apparent that participants wanted to focus more on certain aspects than others and also wanted to introduce additional comments. As a result, two further prompts were added, based on the findings of the pilot and focus group responses. These related to multi-disciplinary communication and to support, both proved to be illuminating in terms of the responses they elicited.

Letters and consents:

- i Access letter/response form
- ii Consent forms
- iii Information sheet
- iv Interview schedule
- v Thank-you to employer
- vi Thank-you to participants
- vii Approvals
- viii University ethical approval letter



Queen Margaret University
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Name and Contact details of the researcher:

Jan Stanier

School of Health Sciences
Queen Margaret University, Edinburgh
Queen Margaret University Drive
Musselburgh
East Lothian EH21 6UU

Email / Telephone: 10009408@gmu.ac.uk 0131 474 0000

To whom it may concern,

Date _____

Research Access

'End of Life Dysphagia Care in Head and Neck Cancer – Speech and Language Therapists' Experiences'

IRAS 131181

My name is Jan Stanier, I am a post-graduate student at Queen Margaret University, Edinburgh. I will be conducting the above research. I am interested in exploring the experiences of Speech

& Language Therapists providing end of life dysphagia care to people with head and neck cancer. In order to conduct this research, I will require access to members of staff from:

- _____ Health Board ☐
- _____ Department ☐

I would like to request your permission for this access. An outline of the proposed research is included in the participant information sheet attached. If you have any queries concerning the nature of the research or are unclear about any question please contact me at Queen Margaret University via the contact information shown above.

If you are happy to agree to this access, please sign and return the form attached.

Finally, can I thank you for taking the time to help me with my research which is much appreciated.

Yours sincerely,

Jan Stanier



Queen Margaret University
EDINBURGH



**'End of Life Dysphagia Care in Head and Neck Cancer – Speech and Language
Therapists' Experiences'**

IRAS 131181

Date_____

Dear Jan,

In response to your letter requesting access to Speech and Language Therapy staff working in

_____Health Board.

☐

_____Department

☐

I can confirm that permission is granted to access these staff in accordance with the documentation provided outlining the area of study and research information.

Yours Sincerely

Signed _____

Please print full name, title and contact information



Queen Margaret University
EDINBURGH



Consent Form

Name and Contact details of the researcher:

Jan Stanier

School of Health Sciences

Queen Margaret University, Edinburgh

Queen Margaret University Drive

Musselburgh

East Lothian EH21 6UU

Email / Telephone: 10009408@gmu.ac.uk 0131 474 0000

To whom it may concern,

**'End of Life Dysphagia Care in Head and Neck Cancer – Speech and Language
Therapists' Experiences'**

IRAS 131181

Please initial boxes

I have read and understood the information sheet (version 1.1, 21/6/13) and this
consent form.

☐

I have had the opportunity to ask questions about my participation.

☐

I understand that I am under no obligation to take part in this study.

☐

I understand that I have the right to withdraw from this study at any stage without giving any reason.

☐

I agree to participate in this study.

☐

Name of participant: _____

Signature of participant: _____

Date _____

Name of Researcher _____

Signature of researcher: _____

Date: _____

cc Participant/researcher



Queen Margaret University
EDINBURGH



Department of Speech & Language Therapy

Royal Alexandra Hospital

Paisley

PA2 9PN

Date

Information Sheet for Potential Participants

'End of Life Dysphagia Care in Head and Neck Cancer – Speech and Language Therapists' Experiences.'

IRAS 131181

Full title of research:

'Managing not Mending: Navigating end of life dysphagia care in adults with head and neck cancer – Speech & Language Therapists' Experiences'

My name is Jan Stanier. I am a post-graduate student at Queen Margaret University, Edinburgh. I will be conducting the above research project. This sheet is intended to provide an outline of the project for potential participants and interested parties.

Starting Premise

The starting premise for this research has an expectation that:

- An exploration of how SLTs experience providing this care will help to reveal what the key issues are for practicing clinicians.
- There is currently a lack of preparation for SLTs providing end of life dysphagia care for adult head and neck cancer patients
- SLT is seen by SLTs themselves to be of value to this area of practice

Aims

Contribute to the SLT profession's ability to meet the needs of this population more effectively by:

- Demonstrating what practicing SLTs report as key issues in delivering this care.
- Providing a basis for supporting the development of future SLT education by identifying SLTs experiences of preparation for this role.
- Contributing to the SLT profession's ability to meet the needs of SLTs by identifying what they think is required to provide this care effectively.

Objectives

The research will therefore explore:

- What SLTs experience when providing this care
- How SLTs experience preparation for delivering this care
- What SLTs feel is required in order to provide this care effectively.

Research Question

What experiences do SLTs have of preparing for and delivering end of life dysphagia care with adult head and neck cancer patients?

Methodology

The research methodology is a qualitative interpretative phenomenological analysis which involves semi-structured and focus group interviews followed by a detailed thematic analysis of transcribed audio data in order to reveal themes and sub-themes thereby seeking to understand the lived experiences of staff working with this group.

Participants

I have identified 12 participants with at least 8 years experience of working as an SLT via purposive sampling to take part in this study, 2 for pilot interviews and 10 main participants. All participants are required to have had clinical involvement with HNC patients at this stage of care within their usual clinical role. All main participants have experience of dealing with at least 6 previous cases where treatment options have become limited or where patients have entered an end stage care situation as agreed by the multi-disciplinary team.

Participation will be via 2 semi-structured pilot interviews, 6 one to one semi-structured interviews, and a focus group of 4 experienced SLT staff selected from the West of Scotland Managed Clinical Network for head and neck cancer SLT sub-group. Each interview will be approximately 45-60 minutes duration and will involve the use of topic prompts. All participants will be asked to consent to providing basic non-identifiable demographic data in order to provide a brief background of each individual. Participants can discontinue or withdraw at any time. All participants will receive a copy of the transcript of their interview following the meeting in order to check that it is an accurate representation of the interview.

Data Collection, handling and Confidentiality

Data collection will be via direct audio recording onto an NHS encrypted laptop. All identifiable data will be anonymously coded and stored on the encrypted laptop in order to comply with local policy. Access will be available only to the researcher and supervisory team. All data will be deleted on completion of the study in discussion with the supervisory team.

Ethics

There is recognition that the topic of the research question involves a sensitive area which may impact on participants and the researcher. As all key participants and the researcher are already experienced, practicing clinicians within the field of head and neck cancer it is anticipated that they will have encountered these topics previously within their practice which may lessen the likelihood of a negative impact of participation in this research. In addition, all local SLT staff participate in peer support activities within the workplace which provides a forum for addressing any issues which may arise. The focus group participants, as part of a wider existing professional group specialising in this area have access to peer support from within the group. The less experienced pilot participants are also local staff working with head and neck cancer and work within an existing professional supervision framework in the workplace which provides opportunity to explore any impact within a supported environment. It is likely that the opportunity to discuss and voice any issues related to the question may in fact be beneficial in terms of providing the chance to share experiences with a fellow colleague and may also contribute to team cohesion as the researcher is team lead. The NHS Research and Development officer has confirmed that NHS ethical approval is not required for this study but an IRAS application has been completed and Research Scotland will co-ordinate access to other health boards re the multi-centre design of the study. Ethical approval is sought from QMU via completion of the QMU ethical approval request form and discussion with the supervisors of the study.

Meetings

If you agree to take part in this study, you will be asked to meet the researcher in order to take part in either a group or one to one interview. Where possible, the researcher will come to you or will meet you at an existing meeting time to avoid impacting on your workplace activities unduly. All participants are free to decline or to withdraw from the process at any stage.

Who has reviewed the study?

This study has been reviewed by the Greater Glasgow & Clyde Research and Development office. NHS Research Scotland has also reviewed the study. Ethical approval has been sought from Queen Margaret University.

If you have a complaint about any aspect of the study

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaints mechanisms is also available to you.

If you would like to discuss this research or ask any further questions please contact either the researcher or supervisor via the contact details below.

To contact someone not directly involved with the study please contact Ms Gillian Sherwood, Lead Nurse, Palliative Care, NHS Greater Glasgow & Clyde via the details below.

If you have read and understood this information sheet and agree to be a participant in the study, please now complete the consent form.

Jan Stanier (researcher)

Professional Doctorate Student
School of Health Sciences
Queen Margaret University, Edinburgh
Queen Margaret University Drive
Musselburgh
East Lothian EH21 6UU
E mail 10009408@qmu.ac.uk

Dr Janet Beck

School of Health Sciences
Queen Margaret University, Edinburgh
Queen Margaret University Drive
Musselburgh
East Lothian EH21 6UU
email JBeck@qmu.ac.uk

Tel 0131 474 0000

Tel 0131 474 0000

Additional Contact not part of the study:

Ms Gillian Sherwood

Lead Nurse, Palliative Care

NHS Greater Glasgow and Clyde

Gillian.Sherwood@ggc.scot.nhs.uk Tel 0141 211 1525

Thank-you for your time and interest



Queen Margaret University
EDINBURGH



'End of Life Dysphagia Care in Head and Neck Cancer – Speech and Language Therapists' Experiences

IRAS 131181

Interview Schedule and Broad Topics

Welcome and introduction (Fire/emergency procedure)

Set up and test of equipment

Set up timing

Record interview identification code at outset – participant initials only and site initials only

Explain:

Set up of audio recording equipment

Format of interview – 45-60 mins, prompt questions

Record participant confirmation of consent and understanding

Option to decline, miss questions or withdraw at any time

No benefit to participation explained.

- 1. Current role**
- 2. Issues encountered with the head and neck cancer client group in relation to dysphagia management**
- 3. Experience of working with people with head and neck cancer who have dysphagia at the end of life**

- 4. Memorable end stage dysphagia cases**
- 5. Difficult issues in providing end of life dysphagia care for the head and neck client group**
- 6. Role description - end of life HNC dysphagia care**
- 7. Most challenging part of end stage dysphagia management**
- 8. Training in relation to end of life**
- 9. Preparation for this type of caseload**
- 10. Professional guidance or information**
- 11. Definition - rehabilitation/palliative care/end of life care**
- 12. Barriers to intervention**
- 13. What is needed (in order to provide effective SLT end of life dysphagia care)**
- 14. Professional issues when delivering end of life care to this group**
- 15. Anything else?**

Stop recording. Thank participant. Explain next stages of process.

Example Prompts

Are you able to explain that a little more for me please?

Can you tell me more about that please?

Would you be able to clarify for me, do you mean.....?

You mentioned that – can you tell me how you felt at the time?

Can you tell me what you were thinking at the time?

Have I understood you correctly, did you mean.....?

Can we move on now to think about.....?

Can you describe how it made you feel?

Do you have any other examples of that?



Queen Margaret University
EDINBURGH



Dear,

'End of Life Dysphagia Care in Head and Neck Cancer – Speech and Language Therapists' Experiences'

IRAS 131181

I am writing to thank you for allowing me access to your staff in order to conduct the above research project. All data has now been collected. On completion of data analysis and evaluation the results will be available. Should you wish to access the outcomes of the research I would be happy to provide further information via the contact details below.

Otherwise, may I thank you once again for contributing to this project. Without your support it would not have been possible.

With grateful thanks

□

Yours sincerely,

(Jan Stanier)

School of Health Sciences

Queen Margaret University, Edinburgh

Queen Margaret University Drive

Musselburgh East Lothian EH21 6UU Email / Telephone: 10009408@gmu.ac.uk 0131
474 0000



Queen Margaret University
EDINBURGH



Dear,

'End of Life Dysphagia Care in Head and Neck Cancer – Speech and Language Therapists' Experiences'

IRAS 131181

I am writing to thank you for participating in the above research project. All data has now been collected and **a transcript of your interview is attached for your reference**. Should you have any comments on the transcript please do not hesitate to contact me.

The study will now enter a data analysis and evaluation phase after which results will be available. Should you wish to access the outcomes of this research I would be happy to provide further information via the contact details below.

Otherwise, may I thank you once again for contributing to this project. Without your support it would not have been possible.

With grateful thanks

Yours sincerely,

(Jan Stanier)

School of Health Sciences

Queen Margaret University, Edinburgh

Queen Margaret University Drive

Musselburgh

East Lothian EH21 6UU Email / Telephone: 10009408@gmu.ac.uk 0131 474 0000

Research & Development
58 Lister Street
University Hospital Crosshouse
Kilmarnock
KA2 0BB

Ms Jan Stanier
Lead Speech & Language Therapist
NHS Greater Glasgow & Clyde
Dept of Speech and Language Therapy
Royal Alexandra Hospital
Paisley
PA2 9PN

Date 25 July 2013
Your Ref
Our Ref KF/KLB/NM R&D 2013AA040
Enquiries to Karen Bell
Extension 25850
Direct line 01563 825850
Fax 01563 825806
Email Karen.bell@aaaht.scot.nhs.uk

Dear Ms Stanier

Managing not Mending: Navigating end of life dysphagia care in adults with head and neck cancer Speech And Language Therapists' experiences

I confirm that NHS Ayrshire and Arran have reviewed the undernoted documents and grant R&D Management approval for the above study.

Approved documents:

Document	Version	Date
SSI form	Version 3.5	01/07/13 signed
R&D Form	Version 3.5	01/07/13 signed
Protocol	Version 1.1	26/06/13
Consent form	Version 1.2	23/07/13
Interview Prompts	Version 1.1	26/06/13
PIS	Version 1.2	23/07/13
Thank you to employer or MCN	Version 1.1	26/06/13
Thank to participants	Version 1.1	26/06/13
Request for Access letter	Version 1.1	21/06/13

The terms of approval state that the investigator authorised to undertake this study is: -

- Ms Jan Stanier, Lead Speech & Language Therapist, NHS Greater Glasgow and Clyde

With no additional investigators.

Date: 05 August 2013
Your Ref:
Our Ref:
Direct Line: 01324 677564
Email: rosemarywilson@nhs.net
R&D ref: FV 728

Ms J Stanier
Lead Speech and Language Therapist
Dept of Speech and Language Therapy
Royal Alexandra Hospital
Paisley
PA2 9PN

Dear Ms Stanier

Study title: Managing not Mending: Navigating End of Life Dysphagia Care in Adults with Head and Neck Cancer – Speech & Language Therapists' Experiences

This letter replaces the original approval letter dated 5 August which did not include the Principal Investigator contact details.

I note that this study involves staff only and does not require ethics opinion. I am pleased to confirm that I formally gave Management Approval to the study above on 05 August 2013.

This approval is granted subject to your compliance with the following:

1. Any amendments to the protocol or research team must have Ethics Committee and R&D approval (as well as approval from any other relevant regulatory organisation) before they can be implemented. Please ensure that the R&D Office and (where appropriate) NRS are informed of any amendments as soon as you become aware of them.
2. You and any local Principal Investigator are responsible for ensuring that all members of the research team have the appropriate experience and training, including GCP training if required.
3. All those involved in the project will be required to work within accepted guidelines of health and safety and data protection principles, any other relevant statutory legislation, the Research Governance Framework for Health and Community Care and IHC-GCP guidelines. A copy of the Framework can be accessed via the Chief Scientist Office website at: <http://www.cso.scot.nhs.uk/Publications/ResGov/Framework/RGFEdTwo.pdf> and ICH-GCP guidelines may be found at <http://www.ich.org/LOB/media/MEDIA482.pdf>
4. As custodian of the information collected during this project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT security policies, until the destruction of this data.
5. You or the local Principal Investigator will be required to provide the following reports and information during the course of your study:
 - A progress report **annually**

NHS Lanarkshire Research & Development: Amendment Approval Letter
Project I.D. Number: L13061

L13061-R&DManagementApproval_250713_Signed Page 1 of 2 **Cont...**

Ms J Stanier
Lead Speech & Language Therapist
Clyde Acute/Head & Neck Team Lead GG&C
NHS Greater Glasgow & Clyde
Department of Speech & Language Therapy
Royal Alexandra Hospital
Paisley, Renfrewshire
PA2 9PN
R&D Department
Corporate Services Building
Monklands Hospital
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date 25th July 2013
Enquiries to Lorraine Windsor,
R&D Facilitator
Direct Line 01236 712459
Email Lorraine.Windsor@lanarkshire.scot.nhs.uk

Dear Ms Stanier,

Project title: Managing not Mending: Navigating end of life dysphagia care in adults with head and neck cancer Speech and Language Therapists' experiences.

R&D ID: L13061

NRS ID Number: NRS13/ON436

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire.

For the study to be carried out you are subject to the following conditions:

Conditions

☐ You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and the Data Protection Act 1998.

☐ The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: <http://www.show.scot.nhs.uk/cso/> or the Research & Development Intranet site: <http://firstport/sites/randd/default.aspx>).

☐ You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.

NHS Lanarkshire Research & Development: Amendment Approval Letter Project I.D. Number: L13061

☐ Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.

☐ You must contact the R&D Department if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.

☐ You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire

☐ You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.

☐ You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.

☐ If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Yours sincerely,

Raymond Hamill – Corporate R&D Manager

cc. NAME	TITLE	CONTACT ADDRESS	ROLE
Dr Nathaniel Brittain		NHS Greater Glasgow & Clyde	Sponsor Contact

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Website: www.nhsggc.org.uk/r&d 1st Floor 38 Church Street
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31/07/2013

Ms Jan Stanier
Department of Speech & Language Therapy
Royal Alexandra Hospital
Paisley
Renfrewshire
PA2 9PN

NHS GG&C Board Approval

Dear Ms Stanier

Study Title: Managing not Mending: Navigating end of life dysphagia care in adults with head and neck cancer - Speech and Language Therapists' experiences.

Principal Investigator: Ms Jan Stanier
GG&C HB site Royal Alexandra Hospital
Sponsor NHS Greater Glasgow and Clyde
R&D reference: GN13ON251

REC reference: n/a

Protocol no:

(including version and date)

Version 1.1 – 21/06/2013

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant Approval for the above study.

Conditions of Approval

1. For Clinical Trials as defined by the Medicines for Human Use Clinical Trial Regulations, 2004

a. During the life span of the study GGHB requires the following information relating to this site

i. Notification of any potential serious breaches.

ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy

(www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

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2. For all studies the following information is required during their lifespan.

a. Recruitment Numbers on a quarterly basis

b. Any change of staff named on the original SSI form

- c. Any amendments – Substantial or Non Substantial
- d. Notification of Trial/study end including final recruitment figures
- e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,
Dr Nathaniel Brittain
Research Co-ordinator
Cc: NRS Permissions CC, R&D Office, Aberdeen



Queen Margaret University

EDINBURGH

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05 July 2013

Dear Jan

Ethical Approval – Managing not Mending: Navigating end of life Dysphagia Care in Adults with Head and Neck Cancer – Speech & Language Therapists' Experiences.

Thank you for submitting documentation in relation to your application for ethical approval for the above project. Your application was considered by the Division of Speech and Hearing Sciences.

Professor Jim Scobbie has reviewed your application and has noted that the project requires approval from the relevant NHS process. He has confirmed that he is happy to grant full ethical approval for your research, subject to confirmation of NHS approval.

A standard condition of this ethical approval is that you are required to notify the University, in advance, of any significant proposed deviation from the original protocol. Reports are also required once the research is underway if there are any unexpected results or events that raise questions about the safety of the research. Please find the appropriate form for this on our website - <http://www.qmu.ac.uk/quality/rs/default.htm#ethics>

We would like to thank you for your co-operation and wish you well with your project.

Yours sincerely,

Sheila Adamson
Secretary to the Research Ethics Panel

Queen Margaret University, Edinburgh, Scotland, EH21 6UU
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ESTABLISHED 1875

N.B in fact this study did not require NHS ethical approval- see Forth Valley approval letter

Example literature search

ASSIA

CINAHL Psychinfo

OVID medline 1946-2015

OVID Medline in process

OVID Medline daily update

OVID Embase

CINAHL

TRIP

Cochrane

Google Scholar

Web of Science

The specific search terms used are shown below:

Speech and Language Therapy

1 'speech and language'

2 SLT

3 SLP

4 'Speech Language pathology'

5 'Speech Language patholog*'

1 or 2 or 3 or 4 or 5

End of life

1 'end of life'

2 terminal

- 3 'end stage care'
- 4 hospice
- 5 palliat*
- 6 dying
- 7 1 or 2 or 3 or 4 or 5 or 6

Head and neck cancer

- 1 cancer
- 2 'head and neck'
- 3 malignan*
- 4 disease*
- 5 tumour*
- 6 1 or 2 or 3 or 4 or 5

Dysphagia

- 1 Dysphagi*
- 2 swallow*
- 3 oropharyn*
- 4 deglutition
- 5 eat*
- 6 1 or 2 or 3 or 4 or 5

Combinations

- 1 all searches combined with 'or'
- 2 all searches combined with 'and'

Table 11 Example of use of Critical Analysis Framework. Langmore, S.E (2009)

Source: date/publication/ credible/where else published	Otolaryngology Clin N Am 42 (2009) 87-105
Title: Concise/informative/clear/is Q relevant	✓ Disorders of swallowing: Palliative care
Author: recognised/qualified/experienced/ why did they write it/ funded by whom	Attempts to define and provide clarity
Abstract: present/clearly IDs problem/states hypothesis/outline methodology	Not stated
Intro: clear aim/problem clear/limitations clearly stated	Not really but adequate
Lit Review: up to date/IDs underlying theoretical framework/balanced +/-/lit clearly IDs need for research/omissions	Multiple papers ?too wide
Hypothesis: does study use experimental approach/can it be tested/is it unambiguous/definitions given	no
Methodology: approach clearly stated/most appropriate/+/- of approach discussed	None stated
Sample selection: subjects IDd/appropriate/location/suitable/generalisable	N/A
Data Collection: adequately described/ validity and reliability of any instruments stated	N/A
Ethics: approval/consent/confidentiality/anonymity method	N/A
Results: what does it show/does it stack up/ results correctly interpreted/relevant/clearly presented	Discusses QOL and pt choices
/internally consistent/sufficient detail re inspiring reader confidence in findings/ images useful	Achieves aim to define, discuss issues, useful
Data analysis: appropriate /stats correct/other variables considered in interpreting apparently significant results/all details present/omissions	N/A
Discussion: balanced/draws on previous research/weaknesses recognised/clinical implications discussed/bias	Appropriate conclusions in summary. Doesn't suggest needs
Conclusions: are they supported by the results/implications Identified	Anecdotal but relevant
Recommendations: do recs suggest further areas for research/ID how any weaknesses could be avoided	?better to have narrower focus

Table 12 Quality Analysis and Categorisation Sheet

Search details	
Study Title and number	
Authors purpose what are they trying to do? Target audience?	
Participants (number, source, allocation, representative?)	
Study Design and methodology (appropriate, robust sufficiently Described)	
Data collection and management (sufficient?, appropriate stats?)	
Time period/ follow up	
Outcome measure (robust?)	
Level of evidence (informal) 1-5	
Contribution/ Relevance/usefulness	
Omissions/ comments/ questions/ bias/funding	
Category (informal) 1 2 or 3 1 best 2 mod 3 poor	
Other notes	

Dissemination

The preliminary findings were shared at the Scottish Partnership for Palliative Care annual conference in September 2014 (www.SPPC) where the project was greeted with interest by a range of professionals including Dr. Derek Doyle with whom I had the privilege of being able to discuss the project on a one to one basis (Figure 4. Appendix pp 237). The project outcome has also been discussed with local undergraduate HEIs who have shown interest in the findings and educational opportunities. The author's involvement in the current RCSLT curriculum redesign reference group and online clinical resources development will also provide a forum for wider dissemination of the findings. The author is a member of a newly instigated Health Board AHP Research and Development Group which it is hoped will provide a further means of disseminating the findings to a wider multi-disciplinary audience.

There are a number of aspects of the findings and recommendations which could be shared via publication such as the discussions regarding risk, team communication, emotional impact and educational needs. This will be explored as a priority.

Finally it would be of benefit to share the findings with other professional groups including Clinical Nurse Specialists and Medical colleagues e.g. via relevant conferences and multi-disciplinary educational events.



Additional findings examples

'A risk worth taking'

- FGA *'I think they are a very complex and diverse group of patients..'* (156-157)
'..that can present at any time..' (159)
- FGB *'... it's a changing assessment isn't it at different stages?'* (677-678)
- P1 *'..I think the style of dysphagia management is different within head and neck than it is ..in the acute setting..'* (130-134)
- M1 *'..so..quite often we're involved in managing their swallowing problems at the end of life and that can take a different role..'* (142-144)
- M4 *'..with somebody who's being treated palliatively ..my role ..is to inform and educate so a patient understands why what's happening is having an impact on their swallow.'* (658-664)
- M4 (re oncology patients with no DG initially) *'..so instead of the other way around where patients maybe have a problem and get better they usually maybe don't have a problem or they have a small problem which gets worse..'* (130-136)
- M6 *'..to some extent they can be predictable problems but you do sometimes get a surprise where.. the problem you think you're gonna have is not there and you have a different problem..'* (138-142)
- M6 *'..I think we have a a huge role in dysphagia management obviously erm particularly with this client group I do think we are a little bit of a breed apart the problems that they have are slightly different from a lot of the erm that you would maybe see in stroke in care of the elderly..'* (121-127)
- M2 *'...and I'm very big on taking an adequate case a really in depth case history if you can get it ..'* (95-97)
- M4 *'..the way I guess I see our role is pretty much what you would do with any patient ...get a history..what's been happening what's going on..speak to the patient to get their perspective..what they would like.. and then you would assess to see what it is you think you can recommend you know their safest..'* (388-399)
- M5 *'..Assessment first of all... discussion with the patient of the result and the potential problems that the patient might have...(371-375)*
'..what my recommendation would be.. positioning.. in terms of how to assist things to go down.. textures always explaining the reason for that..' (375-386)

- M1 *'...I think its gauging what the patient wishes to do despite...high risk of aspiration...listening to what they want to do and then be an advocate for the patient..' (151-156)*
- '...informing the whole team what the dysphagia actually is and how its impacting on the patient...' (374-376)*
- P2 *'...probably in education and facilitating control for the patient and the family..' (response to Q to describe role in eol) (646-649)*
- '...I think the more patients and family understand of what's happening ...and what may happen depending on different ways of continuing..' (with oral intake or without or in a modified way) (649-656)*
- '...that is what can ease peoples' distress and make that whole phase easier..' (658-660)*
- M4 *'...we probably see quite a few patients with.. a dysphagia who we don't expect to really improve (195-196)*
- '...but where our overall emphasis is to try and er maintain or improve their quality of life if they wish to continue eating and drinking, as safely as possible..' (198-200)*
- P1 *'...those.. types of patients end up being the more complex types of patients..' (226-228)*
- P1 *'...erm for example a lot of the patients that we'll be working with will be cognitively intact and maybe a bit more mobile and you know they're making decisions maybe they're a lot younger than the other patients that I've been seeing..' (139-146)*
- FGA *'...but I can't do anything to improve functionally, I would love to be able to but this is what we have and this is where we're at so it's kind of being realistic..' (289-292)*
- M3 *'...they need to know that there ..are lots of healthcare things which actually start to be less important as you get towards palliation or particularly end of life..' (271-275)*
- '...things like ...getting a chest infection which...we absolutely try to avoid at another point in the patient's ...journey there comes a point where..that isn't such an undesirable thing...it helps them if they know that..' (276-283)*
- '...otherwise they...have this firm in their head that there are certain things that they can't do...nurses and therapists have said oh no don't do that don't do that don't do that for the last two yrs...' (283-288)*
- M1 *'...the only thing we could give her was a communication aid in the end but I would say we played a vital role in the education and counseling about her dysphagia..' (543-547)*

- M1 *'...when he went home he was aware that his wife would have to deal with this...but he chose to stay NBM...he was considering other people.'*
(re eol tracheostomy patient dependent on others) (267-273)
- FGA *'..I've had, er er well not fairly recent a patient who had tongue base (referring to tumour site) '..initially with radiotherapy treatment and er had re has recurrence and required tracheostomy erm so like that the space erm for ..' (inaudible one word) '.. is an issue as well as airway protection 'cause he has..' (quietly spoken ? still got) '..a larynx and he was in the acute setting so we were able to asses for access just initially and his swallow was unfortunately unsafe and he he was aware of that..'*

'..and er declined intake oral intake because of how difficult it was..' (454-466)
- FGC *'..That would always be our aim..can they get anything at all..' (873-874)*
- M4 *'..for some people eating and drinking isn't that important at the end of the day but for a lot of other people it is its getting it right for that person..; (768-775)*
- FGA *'..the patient has the bad choking experience...is highly aware..I've had several like that ..' (365-367)*

'..help them make that decision about no thank you I will..leave that just now..' (369-371)
- M4 *'..basically small and regular rather than trying to get down big meals..' (438-439)*
- M2 *'..and keeping their mouth from being dry or breaking down..so giving them fluids through any means..' (195-196)*

'..and making sure they've got things like gel to keep their mouth moist is usually my biggest issue rather than necessarily feeding the patient ..' (196-199)

'..it might sound bad of me to say but the patients comfort first and foremost if the patient is hungry yes I would make sure they were getting something..' (200-203)

'..lots of HNC patients do have gastrostomy insertion for that reason and often it's at radiotherapy point..' (203-205)
- M6 *'..I have another lady in the ward at the moment waiting for hospice, communication's obviously erm part of the remit as well and I do also think we have we have a role there..' (323-326)*
- M1 *'..we can see that your mouth is really uncomfortable and it must be so difficult not being able to speak to your husband at this point in time..'*

‘...er the only thing we could give her was a communication aid in the end but I would say we played a vital role in the education..’

‘..and counselling about her dysphagia ..’ (538-547)

FGC *‘...if someone didn’t have capacity I could see that being a very..’ [sighs and laughs] (650-653)*

M4 *‘..it may be that some pts are able to tell you a bit more easily than others what it is that they want I think probably one of the more difficult challenges is pts who have a cognitive impairment ..approaching end of life who..don’t really understand why you’re making these recommendations/why they’re not allowed to eat and drink/why they can only eat/drink certain things so it’s complicated by those kind of issues ..’ (719-730)*

M5 *‘..end of life care I think should be partly like palliative helping the patient cope with the stage that they’re at pain free, and with as much dignity as possible...and allowing and giving them the information that they can make their own choices ..’ (619-624)*

M6 *‘..I feel I’ve made a difference to the carer in giving the carer permission for certain things..’*

‘..for example erm the patient is going to die very soon the patient would like a sip of water for whatever reason..’ (1133-1138)

M6 *‘.. I think we might have a role in giving permission now does that have to be an SLT but I think that if the SLTs been heavily involved in the swallowing front then the carer or the patient might be looking for the SLT to make the call erm so I think there could be a role there..’ (1147-1154)*

‘Under your skin’

P1 *‘it’s actually quite nice...’cause you get to know them’.*

P1 *‘..you hear people saying I don’t know how you could do that..’ (re SLTs) (1012-1013)*

FGC *‘..managing the disappointment..’ (791)*

FGC *‘..the distress..’ (re managing patient who wants to eat but can’t) (793)*

P2 *‘..it might be quite hard going if I was to do more work with end of life people..’ (1123-1125)*

- ‘...there’s no doubt it’s very nice when people are doing well and going forward..’ (1125-1127)*
- M6 (re memorable end stage cases) *‘..some of the younger age patients..’(331)*
- P2 *‘..and you’re so afraid you’re going to put your foot in it...in case family/medical staff have been holding back the exact seriousness of their condition..’ (460-466)*
- ‘..if you were to accidentally be the one to let them think things were worse...that would be dreadful..’ (474-478)*
- ‘..I’m just very aware of my own reticence over the years as a I don’t think I’ve I fully understand that yet...’ (625-627)*
- ‘...I think partly it is self-consciousness talking to people..’ (628-629)*
- P2 *‘..it might be quite hard going if I was to do more work with end of life people..’ (1123-1125)*
- P2 *‘...there’s no doubt it’s very nice when people are doing well and going forward..’ (1125-1127)*
- ‘...it may prove to be very satisfying...if you can make people feel better at that point...it’s worth a lot more perhaps than at other stages..’ (1130-1133)*
- M3 *‘..you just try to think about it from first principles..you start to think about what the ..needs of the patient are ..that..where it always comes down to isn’t it..you’re trying to think of what the patient is likely to need and then you see if you’re the person that can offer something in that area..’ (887-896)*
- M3 (re patients choosing to stay on acute ward at eol) *‘..if they’re in a single room ...before they get to end of life...’ 582-584)*
- P1 *‘..it’s a bit scary but I think maybe just time..’ (1015-1016)*
- M4 *‘..what we would love to be able to do is to go in and say right you try this and and hopefully they’ll be able to take something..’ (308-310)*
- M2 *‘.. it was just positive to be able to say it’s been good knowing you it’s been a journey but we’ve shared that or I’ve been privileged to share that with you so it was the first time it had happened in all these years..’ (802-810)*
- M4 *‘..they’ve got enough going on erm yeah it’s tricky..sometimes..’ (513-514)*
- P2 *‘..so that’s my main frustration but also on a very well personal level, it does affect your job satisfaction..’*
- ‘..and erm the fact that you may have spent quite a bit of time with someone made careful decisions gone to a lot of effort to communicate the thinking behind the decision..’*

‘..in both your verbal and your written communication for that then to be disregarded without discussion it seems to be a one way street in terms of er professional respect..’

‘..and personally I do find that challenging..’ (257-273)

M6 *‘.. we have some members of the team who have a what I would consider to be an old fashioned attitude in that it doesn’t erm take appropriate cognisance of the value of the team as a team..’ (438-441)*

FGC *‘...sharing with colleagues, I job share...I suppose peer support and with your line manager...chatting things through and talking to other people to see if there’s anything else any new ideas..’ (1342-1346)*

M1 *‘..I guess if I was erm concerned that I wasn’t too sure how I should be managing a complex end of life HNC DG patient then I’d pick up the phone to my colleague..’ (1200-1206)*

‘Communication isn’t always wonderful’

P2 *‘..I think I quite like working in in head and neck because I think there’s a bit more pragmatism than there are with compared to other caseloads within SLT..’ (133-136)*

‘..the idea seems to be that SLTs would like everyone to be NBM..’ (241-242)

‘..we are super over cautious ..way we make decisions..’ (243-244)

‘..you may have spent ..time..careful decisions..lot of effort to communicate the thinking behind the decision..’ (261-265)

‘..in ...verbal and written communication for that to be disregarded without discussion...’ (267-269)

‘..it seems to be a one way street in terms of professional respect..’ (269-271)

‘..I do find that challenging..’ (273)

‘..Sometimes we acquiesce..’ (re medics changing SLT advice) (281-289)

‘..more with our patients I just see the patient separately..’ (283-285)

M6 *‘..perhaps at times advice that’s been given not being followed or not even being given any cognisance at all..’ (374-378)*

‘Trained and Equipped’

- P1: *‘..mm well I have had valve training I’ve had specifically really to to this job that was a new thing I just started..’*
‘..ten months ago and I I’ve done a fair amount of shadowing..’ (713-718)
- M4 *‘..so yeah that’s been kind of hands on..’ (533)*
- M1 discussed a perception within the MDT that SLTs were not needed and that patients should just be allowed to eat because they were end of life.
- M1 *‘..maybe just feeling a little bit under-valued as to what our role is..’ (503-505)*
- P2 *‘I think the assumption always has been people want to eat and drink if they’re at that stage they don’t mind what it does to their chest so they don’t need information from the SLT about what will lessen the effect on their chest ‘cause they don’t care about it anymore its academic..’ (99-1003)*
- M6 *‘..I took every opportunity to do that erm I would always go along... there was usually some sort of relevance..’ (760-763)*
- P2 *‘..I don’t think I’ve had anything specific..’ (re eol DG training) (710-712)*
- FGA *‘..there’s an undergraduate half day on DG..practical placement..so it’s not a lot..’ (941-944)*
‘..They don’t get anything it’s not enough..’ (947)
- P2 (SLTs) *‘..probably need to be available not just for acute in patients...available to hospices..domiciliary as we hope to get more people home as they’re approaching that phase..’ (1021-1026)*
- FGC *‘..Yeah probably and time as well it’s a huge time pressure...it’s really difficult..’ (1050-1051)*
- M3 *‘..we need good multi-disciplinary team communication.. that’s almost full stop..’ (1170-1173)*
- P2 *‘...that would deal with ...you need to know who might benefit from you..’ (1020-1021)*
- M6 *‘..I think that the the MDT should be as as wide as it needs to be I do sometimes think that we don’t have all the people in the team on a regular basis that we could have..’ (1478-1482)*
- P2 *‘..It would need to have a strong kind of liaison ethos..’ (re what an eol DG service would need) (1014-1015)*
‘..very strong mindset for team working ‘cause you need to...know who ...might be involved..’ (1027-1029)

- M5 *'.. I think it would be beneficial if there was more formal rather than informal training..' (787-790)*
- M6 *(re knowledge of end of life) '...that knowledge may be out there but we just don't have it so...' (1264-1265)*
- P2 *'..I can't see us having something at that point but now I think I would..' (423-425)*
- P2 *'..I would think differently for some patients perhaps not all..' (427-428)*
'..your input isn't requested because other people maybe assume that there's nothing you can add at that stage..' (970-973)
'..maybe I was of the same mindset in the past..' (nothing we can add) (974)
'..I think the assumption always has been people want to eat and drink if they're at that stage they don't mind what it does to their chest so they don't need information from the SLT about what will lessen the effect on their chest 'cause they don't care about it anymore its academic..' (997-1003)
'..I do think probably that might change,, ' (1005)
- P2 *'..I think it's difficult for us...probably because traditionally we haven't been on equal footing with the medics and I hope that will change over time...' (1172-1174)*
'..I think there's a place for acknowledging what we would prefer to recommend but...maybe ...colleagues would have a different priority or agenda..' (592-596)
- M3 *'...one of my modules was PC...just the opportunity to study my ...caseloads...in much more detail has ...really kind of pushed me forward in understanding and really valuing the multi-disciplinary approach and being a good team player..' (198-204)*
- FGA *'Black and white' (re probe about changed management) (741)*
- FGC *'.. No/not at all ready/not at all/ it was a very basic level dysphagia that you were trained in..' (group response to prompt re preparation for caseload in under-graduate and professional training) (922-926)*
- M6 *(what is needed) '...really good communication between members of the team erm because obviously we are not a daily fixture for patients who are in that position.. you could have a patient who you know well who you could offer something to and you don't even know they're at that stage or they're in the hospice or whatever..' (1300-1307)*
- FGA *'...our junior therapists are getting a spread of experience so that...they have skills across the board..' (1178-1180)*

Some participants related accounts of their own changing views about the role in end of life care (P2, M3) whilst others described a changing professional landscape regarding SLTs working in this field. (FG, M4).

P2 and M3 both described how their individual views had changed over a period of time. P2 as a result of exposure to the caseload and peer support from more experienced colleagues and M3 as a result of further study. P2 volunteered that she had previously been comfortable with not being involved in end of life care issues and had felt that there was no role for SLTs at this point leaving the decision making to medical staff. P2 described having 'changed her mind' after having felt strongly that there was no role for SLTs in end of life care.

P2 *'..my (senior) colleague's insight..' (397)*

'..that did change my mind a bit before I had always felt strongly that there's not a role..' (418-421)

'I think I probably had a bit of a different mindset you know five or six years ago..' (745-747)

'..and it has changed..' (749)

M3 *'..that's an area where I personally feel ..my input my understanding my..evaluation of my role I think that's really changed in the last ..maybe 4 yrs 5 yrs..' (189-193)*

'..yeah..it's changed for 2 reasons...the main reason its changed is because I've been doing more study...' (identifiable info) (195-198)

'..one of my modules was PC...just the opportunity to study my ...caseloads...in much more detail has ...really kind of pushed me forward in understanding and really valuing the multi-disciplinary approach and being a good team player.' (198-204)

'...I think I understand why that's important much more I think I thought it was optional before..' (207-208)

P2 described a view that within the MDT there was the assumption that all patients want to continue oral intake. P2 later discussed a need for engaging with the patient to enable them to make informed choices about whether or not to continue oral intake and

for the team to consider that some people may prefer not to continue once informed of the potential associated risks of doing so. P2 discussed her view of how the SLT is viewed within the MDT suggesting that referrals were not made due to a lack of awareness of what the SLT could offer. P2 commented on 'not being on an equal footing with the medics' and issues with differing priorities across healthcare professionals and a hope that this might change as a result of awareness raising within the team. P2 suggested that the SLT role would include advice, education, and support through all stages of care.

It is worth considering whether P2s initial stance reflects the earlier discussion about the potential for P2s own personal experiences having influenced how she viewed the role for SLTs within end of life care.

M3 suggested that her individual views had changed as a result of further study which had raised her awareness of the importance of MDT working. M3 appeared to suggest some responsibility with the SLT to address this which is in contrast to P2s view which only touches on the perceived failure of colleagues to recognise the SLT role. M3 is more experienced than P2 so this may account for her ability to see the issue within a wider context rather than only at a personal experience level.

The focus group took this a step further in suggesting that some colleagues did not wish to refer patients with C suggesting that this was due to a desire to avoid SLTs advising that the oral route was unsafe or recommending modified diet options which were perceived as being undesirable to some colleagues at this stage of care. The focus group went on to discuss this issue sharing their own local experiences and ultimately suggesting that this type of situation was changing and now occurred less frequently than in their previous experience. They also commented on the professional development of the clinical area of dysphagia as a whole within SLT suggesting that the area had changed in the last ten or fifteen years with the SLT now working much more as part of the MDT than in the past. In addition, the focus group commented on a shift in the professional view of dysphagia with a move towards taking into account patient views and risk management becoming more commonplace in recent years. The focus group commented on the need to adjust advice as the patient's condition progressed towards end of life.

- FGC *'..I think sometimes they don't want us to assess..' (re consultants) (693-696)*
- FGC *'..they don't want an SLT assessment in case you would recommend thick, limited recommendation either oral intake is unsafe or...' (705-709)*
- FGA *'..I think it's certainly changing in our service I I don't have that..' (710-711)*
- M4 *'..so I think it's much more recognisable as a phenomena now than maybe it was when I was training..' (564-567)*
- FGB *'..I would say that's changed..when we started with DG management many years ago it was definitely a case of it was NBM if there was the risks...that has changed within our management..' (721-725)*
- FGC *'..I mean we wouldn't so much ..recommend NBM but if you're asked an opinion on risk and aspiration then you're giving them that..' (726-734)*

General comments on transcripts

P1

These comments have an almost apologetic tone with obvious hesitancy and some uncertainty (use of 'I suppose' and 'in some way'). There is a sense that the participant may feel that a counseling role is not appropriate for SLTs particularly in the use of the word 'actually' as if in response to some negation of the comment. The need to state that 'we do a lot of positive work' may also project a sense of some lack of professional confidence as does the comment about having a 'tiny role'. This participant was very new to working in head and neck cancer and may have been adjusting to this new role at the time of the interview. As a result, this interpretation needs to be viewed within the wider context and as part of the data corpus.

P2

This participant described having changed views on the SLT role in end of life dysphagia. Throughout the interview there was a sense of holding back what the participant really wanted to say. At some points however, obvious frustration became apparent. This was evident throughout the interview and in fact some of this participant's comments appeared to represent something of an anomaly in terms of the level of apparent frustration demonstrated. On closer inspection of the interview and context there is a sense that this participant feels considerable frustration with the MDT and in particular with medical staff. This may be a reflection of the participant's position which may have been viewed by the participant as not readily allowing an option to influence how to address such issues. This sense of frustration also extends to patients in some cases. The participant later reveals a personal sense of discomfort with the client group which may have some relevance to the expression of frustration if there is some mismatch between the participant's personal sense of role and fit and the duties assigned. If this interpretation has basis, it may also have influenced the comments about not having considered the end of life role as being 'a separate entity'. This may of course not be the case but if the participant has expressed discomfort with the end of life caseload, it may be more easy to consider it as part of the usual job and thereby avoid having to consider more sensitive management decision making.

Aside from recognition of these potential issues, the participant clearly has a sense that the SLT role involves a considerable educational component both in relation to patient and carers and fellow professional colleagues. There is also a clear sense that facilitating patient led decision making is a key aspect of the SLT role.

FG

It was clear in the focus group that one participant was more vocal than the others which made it challenging for the researcher to gain a sense of individual views. Participant C demonstrated at least one example of changing the original statement to align with the dominant speaker. It appears that participant C modified the initial stance of describing interactions with medical staff regarding a recommendation that oral intake is unsafe and later states that '*...I mean we wouldn't recommend nil by mouth...*' in response to participant B stating '*...I don't have that*'

In spite of this there was consensus that the role is challenging and variable with an overall emphasis on maintaining the safest possible swallow for patients. There is also consensus that the role includes preparation of the patient for future changes. An underlying recognition of the difficulties around managing patient expectations and risk management also appears in several comments about supporting patients for future changes. The tone of these particular comments was interpreted as something of a shared anxiety around managing such situations. The participants seemed to be benefitting from discussing the issue openly together and looked to each other for confirmation during the interview. This was interesting and reflected the later discussion around support and the benefits of peer discussions.

This interview demonstrates the difficulty encountered when focus groups include characters with differing levels of confidence to participate and necessitated more intervention from the researcher in order to attempt to mitigate this effect.

M1

This participant's views clearly align with the pilot and focus group participants in discussing a counselling, education and facilitatory role in enabling the patient to make decisions. This participant further goes on to discuss the role in an advocacy sense in stating that the SLT is the voice of the patient. This is quite a strong stance to take as adopting this role assumes considerable responsibility for accurately reflecting the perceived voice of the patient. M1 also makes the comment that this area of work is 'not a huge difference' from other areas of swallowing management however, in choosing to say 'not a huge difference', this participant does seem to acknowledge that some difference exists.

M2

M2 also makes reference to an advocacy role and further describes this extending to acting as an advocate for the patient with their family. This comment also reflects previous statements from earlier participants regarding the need to consider how easy it is for patients to communicate their preferences which seems to be an issue for some patients depending on their particular circumstances.

This participant also describes having an 'intermediary' role within the MDT which also alludes to this issue in that the therapist appears to have taken on the role of speaking for the patient.

M3

Participant M3 makes reference to patient communication but this was not explored further as it was not the focus of the study however, it is clearly also an area of concern to participants as several made the point that decision making is challenging if the patient is unable to communicate their views effectively.

This interview supports the earlier participants in describing the role as including an advocacy component in the statements about 'leading' the 'opening up' of discussions with colleagues. There is also evidence that the participant views the role as including education, counselling and patient led decision making. Participant M3 expresses the nature of patient led decision making in more detail and describes how discussions about management are approached when the SLT changes recommendations and perhaps relaxes previous advice including giving 'permission' to make changed decisions at this stage. This is presented sensitively by the participant who demonstrates confidence and empathy in dealing with what could be perceived as a turnaround and has the potential to lose the patient's confidence in SLT advice if not fully explained and justified. Participant M3 also talks about the need to re-assess at intervals rather than making a recommendation and sticking with it purely on the basis that someone is near the end of life. This participant is highly experienced and appears confident to initiate and manage these ethically difficult areas which may not be the case for all participants.

M4

Participant M4 volunteered less on the topic of role with more general statements and apparently a less confident or assured view than participant M3. There is however a recognition of the need to tailor the SLTs input to the individual and consensus on the aim to maintain the safest swallow possible in the context of maintaining the optimal quality of life for the patient. This participant also states a view that the role includes an educational component which resonates with previous interviews. The statement about 'knowing what it is we are trying to achieve' is unclear in that it is not obvious whether this is a simple statement about what is being considered in decision making or whether there is some underlying lack of clarity about what the professional role entails.

M5

This participant considers assessment to be a key aspect of the role and again describes a role in preparing and reassessing the patient for future change.

M5 also describes the role in terms of sharing information with the patient which is demonstrated strongly across the data corpus.

Use of the phrases '*at a distance*' and '*stepping in*' would seem to convey a desire to avoid undue intervention. The participant appears to be referring to the need to avoid intervening unless required. This may reflect an awareness of the need for the patient to retain some independence and freedom from healthcare personnel but may also reflect some sense of reluctance to become involved at this stage of the care process.

M6

Participant M6 also supports the view of the role involving patient led decision making and quality of life and further goes on to talk about a role in 'giving permission' to the patient which appears to refer to explaining a relaxation of previous advice which was also mentioned by participant M3. Interestingly, both M3 and M6 are highly experienced SLTs who both exhibit confidence in approaching these sensitive management issues. It is possible that this type of issue is one which becomes more apparent to SLTs after extensive exposure to the client group and may not be something that those new to the field would approach so readily. It may seem less likely that participants P1 or P2 would initiate this type of approach and may instead choose to take a 'safer' decision making choice. The comment about patients looking to the SLT 'to make the call' regarding giving permission raises the issue of power relationships and ownership. Is it the case that patients do not feel they can make these decisions independently and if not why not?

This participant also raises the issue of when end of life begins and reports this as 'the crux' of the issue. This may reflect the level of experience of this participant in that there is more evidence of an awareness of wider issues within the palliative care field, one of which is discussion around when end of life starts.

The interview also includes some comments about 'a supportive function' which may align with previous comments about a counselling role. In spite of this participants high

level of experience however the interview also appears to show some uncertainty around whether this is in fact a legitimate aspect of the professional role in the comment

'...even if we're not as a professional with a specific remit...' and

'..there is something about a two minute kind of you know..' (referring to going to see patient at eol) (1097-1103)

This participant also introduces the idea of the influence on the SLTs choice of interaction in relation to the depth and length of involvement and again suggests some sense of a lack of clarity of the professional role in the comment about *'not actually doing anything'*:

(start/end of SLT role at eol) '...I think it might vary a little bit ... think to myself does it vary a little bit dependent on how involved you've been with the patient are you just popping your head round the door 'cause you know them really well and you are you're not actu actually actively doing anything.' (1088-1096)

Participant M6 also comments on communication and aligns with participant M3 in suggesting a concern about a patient's ability to communicate their wishes:

M6 *'..communication wise difficult one... I could foresee you might go in and see an option for encouraging the patient to be able to get a message across..' (1156-1160)*